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Physical Health and People with an Intellectual Disability – A Qualitative
exploration of their experience of trying to live healthier lives, and of the
NHS Learning Disability Annual Health Check

James Andrew Bodel

A thesis submitted in partial fulfilment of the requirements of the degree of Doctorate in
Clinical Psychology

Coventry University, Faculty of Health and Life Sciences, University of Warwick, Department
of Psychology

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List of Abbreviations

AHC	Annual Health Check
APA	American Psychological Association
ASD	Autism Spectrum Disorder
CFS	Chronic Fatigue Syndrome
CINAHL	Cumulative Index of Nursing and Allied Health Literature
DSP	Direct Support Professional (carer)
GP	General Practitioner
HeSPID	Healthy Settings for People with Intellectual Disabilities Framework
HSCPs	Health and Social Care Professionals
ID	Intellectual Disability
IPA	Interpretative Phenomenological Analysis
NCD	Non communicable disease
NGT	Nominal Group Technique
NHS	National Health Service
OECD	Organisation for Economic Co-operation and Development
PPRQ	Provider-Patient Relationship Questionnaire
PRISMA	Preferred Reporting Items for Systematic Reviews
SGD	Speech Generating Device
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Declaration

This thesis, both the systematic literature review and the empirical chapter, was conducted under the supervision of Dr Anthony Colombo (Assistant Professor in Clinical Psychology, Coventry University and The University of Warwick). Dr Colombo also provided critical feedback on draft copies of the systematic literature review and empirical chapters.

Helen Webb (Counselling Psychologist), Dr Sean Slater (Clinical Psychologist), Dr Katherine Byron-Daniel (Clinical Psychologist) and Jayne Davies (Learning Disability Liaison Nurse) assisted in the development of the empirical research topic. Helen Webb further supported the empirical chapter by facilitating a bracketing interview. In addition, a fellow trainee acted as a second rater for the quality assessment of studies included in the systematic literature review.

Apart from the collaborations noted above all material presented in this thesis is my own work.

Summary

This thesis explores people with an intellectual disability's efforts to live healthier lives. As a population they have unmet health needs, experience poorer physical and mental health outcomes, a higher prevalence of chronic health conditions, and an increased risk of premature death that is on average 16 years earlier than the general population. This thesis aims to contribute to the literature concerning the support offered to people with an intellectual disability as they seek to promote their health.

The first chapter is a systematic literature review exploring how people with an intellectual disability experience trying to live healthier lives. Findings from 12 studies were critically evaluated and synthesised using a meta-ethnographic approach. Analysis resulted in the development of two interpretative themes summarising a reciprocal synthesis of an insider perspective held by participants with an intellectual disability, and an outsider perspective held by their carers regarding efforts to live and promote healthier lives. Each theme is explored and a line of argument synthesis presented, followed by recommendations for practice.

The second chapter presents an Interpretative Phenomenological Analysis study seeking to understand the experience of the Annual Health Check process from the perspective of people with an intellectual disability. Twelve adults with an intellectual disability participated in semi-structured interviews. Analysis of the transcripts led to the development of three superordinate themes. Six subordinate themes are identified and discussed. Findings suggest that people with an intellectual disability attend Annual Health Checks with health-related goals. A satisfactory health check is characterised by an inclusive approach by all primary care staff that both supports these goals and communicates that the goal is shared. Clinical implications and areas for future research are discussed.

The third chapter presents a reflective account of parallel experiences as a trainee, a clinician, and a novice researcher, and how they overlapped while completing a doctoral thesis. The authors' personal experiences are described in relation to managing these different roles and the competing demands that come with them. The chapter concludes by reflecting on these experiences from the perspective of Acceptance and Commitment Therapy and how psychological distress is formulated within this approach to intervention.

Chapter 1: Systematic Literature Review

How do People with an Intellectual Disability Experience Trying to Live Healthier Lives: A Meta-Ethnographic Review

This paper will be adapted for submission to the Journal of Intellectual Disability Research.
(See appendix 3 for Author Guidelines)

Word count (excluding tables, figures and references): 7939

Introduction

Research Aim and Significance

This review aims to synthesise the existing evidence exploring how people with an intellectual disability (ID) experience trying to live healthier lives. People who receive an intellectual disability diagnosis have significantly lower than average cognitive abilities that contribute to difficulty understanding new or complicated information, learning new skills, and coping independently (Hatton et al., 2017). These difficulties are usually apparent from childhood, and people who receive the diagnosis require varying levels of support to manage everyday activities that rely on attention, memory, and reasoning skills (Sitbon et al., 2018).

A healthy lifestyle describes a set of behaviours that contribute to both a lower risk of ill health and the maintenance of physical, mental and social well-being (Blomqvist et al., 2018). While a full description of these behaviours in health promoting contexts would involve all aspects of human life, the term healthy lifestyle is commonly used to describe a combination of sufficient physical activity (at least 30 to 45 minutes of moderate physical activity each day, e.g. a brisk walking pace or cycling with light effort), healthy eating (a nutritious diet low in salt and sugar coming mainly from plants, and no more than 30% from fats), drinking less alcohol and stopping smoking (Berra et al., 2017; World Health Organisation, 2019). These health promoting behaviours, in combination with maintaining a body mass index of between 18.5 and 24.9, are typically considered to represent a healthy physical lifestyle (Mehta & Myrskylä, 2017).

There are approximately 1.5 million people in the United Kingdom (UK) who have received an intellectual disability diagnosis (Office of National Statistics, 2018). Collectively, they face many barriers to living a healthy lifestyle that include unmet health needs (Chapman et al., 2018), poorer physical and mental health outcomes (Edwards et al., 2018), a higher prevalence of chronic health conditions (including type 2 diabetes, cardiovascular disease, respiratory disease, and osteoporosis;

Hanlon et al., 2018), and an increased risk of premature death that is on average 16 years earlier than the general population (Welyczko, 2018). Several factors contribute to these health disparities such as unequal access to preventative and timely healthcare (Casson et al., 2018), greater exposure to social determinants of poor health (e.g. unequal access to housing, unemployment and greater levels of social exclusion; Friedman, 2021), and higher rates of obesity (Scott & Haverkamp, 2016). People with an intellectual disability are also less likely to engage in health promoting behaviours and more likely to engage in unhealthy behaviours compared to their non-disabled peers (Scott & Haverkamp, 2016).

The Relationship between Physical and Mental Health

The World Health Organisation's definition of health is inclusive of mental health, with physical and mental health representing two sides of an intrapersonal well-being 'coin' (Eriksson & Lindström, 2008). Even low levels of physical activity are associated with a reduced risk of mental health problems, and regular exercise is recommended for the prevention and management of mental health diagnoses (Teychenne et al., 2020). The long-term impact of a chronic physical condition unsurprisingly includes changes in mood, anxiety, and the experience of loss. Where these subjective changes persist or intensify, they may result in the person receiving a mental health diagnosis (Marks et al., 2018).

People with an intellectual disability experience a greater prevalence of mental health problems (up to 7 times that of the general population) and, due to the cognitive difficulties the diagnosis describes, have greater difficulty accessing talking therapies (Vereenoghe et al., 2018). Recent UK statistics also indicate that people with an intellectual disability are less likely to experience improvement following psychological therapy (Baker, 2020). The high prevalence and persistent nature of these difficulties, and the treatment challenges, indicate that additional approaches to intervention are required for this group of people (Vereenoghe et al., 2018). With the ideal being prevention, efforts that successfully support physical well-being also

support mental well-being and reduce the risk of psychological distress (Das et al., 2016).

Review of Existing Literature

As awareness of the health disparities experienced by people with an intellectual disability has grown, efforts to reduce their risk of ill health and improve outcomes have increasingly focused on promoting healthier lifestyle behaviours.

Willems et al. (2017) conducted a systematic review of interventions aimed at increasing the levels of physical activity and healthy eating. Of the 45 studies included the majority focused on the use of behaviour change techniques. Most often these were providing information, planning for support and providing instruction. The review concluded that efforts targeting single health behaviours or determinants of health tended to be ineffective in changing health outcomes for people with an intellectual disability. The authors noted that a guiding theoretical framework was typically absent, and that future efforts should be theory driven to improve effectiveness.

Harris et al. (2018) conducted a systematic review and meta-analysis of research on weight management interventions for adults with an intellectual disability. Six randomised control trials were included, none of which successfully incorporated all clinically recommended components for weight loss (e.g. a daily caloric energy deficit of 600kcal, regular physical activity and behaviour change techniques). None of the interventions demonstrated effectiveness compared to no treatment. The non-significant results were thought to be due to the heterogeneity of both the study designs and the participant population, introducing numerous confounding variables. The lack of adherence to clinical guidelines, particularly the absence of an energy deficit diet, and the recommended level of weekly physical activity, was thought to be a major limitation of the included studies. Adults with an intellectual disability diagnosis encounter additional barriers to engaging in physical activity of any intensity (Scott & Haverkamp, 2016). They are therefore less likely to do so and the

reasons for this need to be understood for weight management interventions to be successful.

Kuijken et al. (2020) surveyed care and health professionals regarding small scale health promotion initiatives for people with an intellectual disability living in formal care settings. In total 47 initiatives were identified, with the majority focused on increasing physical activity and none on increasing health knowledge. The researchers noted two factors that may have affected the success of these initiatives. The first was that while most tended to host organised activities in a community location, the majority of people with an intellectual disability who were offered these activities were living in group home settings. Little consideration appeared to have been given to how organisational and logistical limitations could affect the ability of people to attend. The second was that none of the initiatives appeared to account for the potential role of existing behavioural norms or the influence of others within these settings had on the health behaviours of people with an intellectual disability. The authors suggest that these factors may have hindered efforts to embed healthy behaviours into the daily lives of people with an intellectual disability.

Rationale and Research Question

There are three main limitations of the previous literature. First, rather than accounting for and situating themselves within the daily context of people with an intellectual disability, most interventions are short lived programs outside the living environment. No systematic review has so far explored how people with an intellectual disability experience health promotion outside these programs. Second, compared to their non-disabled peers, the daily lives of people with an intellectual disability, and their efforts to live healthier lives, are likely to be affected by their additional needs and the support services they access. No previous systematic review has focused on how this support influences the efforts of people with an intellectual disability to live healthier lives. Third, though it is acknowledged that adults with an intellectual disability encounter additional barriers to achieving a

healthier lifestyle compared to the general population, no previous systematic review has focused on their day-to-day efforts to overcome said barriers.

To address these limitations this review aims to answer the question “How do people with an intellectual disability experience trying to live healthier lives?” by critically reviewing the qualitative literature in this area.

Methodology

Systematic Literature Search

A systematic search of qualitative literature exploring people with an intellectual disability and their experience of efforts to live healthier lives was conducted in February 2021. The databases APA PsychArticles, APA PsychInfo, CINAHL, MEDLINE, PubMed, and SCOPUS were searched. The search was inclusive of unpublished doctoral theses within these databases. The reference sections of retrieved publications were also reviewed for relevant literature not returned by database searches.

The search strategy was designed using the SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation and Research type), created to improve the clarity and replicability of systematic searches (Cooke et al., 2012). Table 1.1 (overleaf) details the search terms used for each section of the SPIDER. The search strategy was split to accommodate all identified synonyms. This involved searching each database separately using the five sets of search terms numbered 1 to 5 in the phenomenon of interest section of table 1.1. The combined search terms can be viewed in Appendix 1.1.

Table 1.1 SPIDER Tool and Search Terms

SPIDER Tool		Search Terms
Sample	People with an intellectual disability diagnosis	"learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*"
Phenomenon of Interest	<ol style="list-style-type: none"> 1. Healthier lifestyle 2. Physical activity 3. Diet 4. Stopping/reducing alcohol 5. Stopping smoking or use of other health harmful substances 	<p>"health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*"</p> <p>exercis* OR fitness OR active* OR "physic* activ*" OR cardi* OR "cardi* fitness"</p> <p>diet OR "health* diet" OR "health* eating" OR "balanced diet" OR nutrition* OR "nutritional intake" OR "nutrient balance" OR "calor* reduction" OR "calor* restriction" OR "fresh produce" OR fruit* OR vegetable* OR fibre OR fat OR sugar OR "junk food" OR "high-fat foo*" OR "sugary foo*" OR "sugary drinks" OR "soft drinks" OR "saturated fat" OR "fatty foo*"</p> <p>"reduc* alcohol" OR "sto* alcohol" OR alcohol OR "lowering alcohol"</p> <p>"reduc* smoking" OR "sto* smoking" OR smoking OR cannabis OR marijuana OR "soft drugs"</p>
Design	Interviews, semi-structured interviews, focus groups	interview OR "focus group" OR "mixed metho*" OR qualitative
Evaluation	Attitudes and/or experiences of healthy lifestyle behaviours	attitude OR experience OR belief OR view
Research	Qualitative and qualitative components of mixed methods	"mixed metho*" OR qualitative

Inclusion and Exclusion Criteria

The studies returned by the systematic search were reviewed and retained or removed based on the inclusion and exclusion criteria listed in table 1.2.

Table 1.2 Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Sample	People with an intellectual disability as their primary diagnosis Adults (18 years and older)	People whose primary diagnosis was not an intellectual disability, even if the face similar health challenges (e.g. Down's Syndrome) Children (under 18 years old)
P of I	Attitudes towards a healthy lifestyle Primary focus on healthy lifestyle behaviours in daily life Study clearly differentiates the contributions of participants with an intellectual disability from those of carers	Any topic not related to healthy lifestyle behaviours Any topic related to a healthy lifestyle intervention Health behaviours related to a chronic condition Substance use related to addiction Study does not provide enough detail to distinguish the contributions of people with an intellectual disability from those of carers
Design	Interviews, semi-structured interviews and focus groups, mixed methods	Pre and post intervention, survey or questionnaire only
Evaluation	A focus on attitudes towards and experiences of healthy lifestyle behaviours	Quantitative outcome measures only
Research	Qualitative and qualitative components of mixed methods research Research published between 2010 and 2021	Quantitative research only Research published prior to 2010

Studies were included if they were written in English, had passed through a process of peer review (both doctoral dissertations and journal articles), and were published between 2010 and February 2021. No restrictions on the gender or ethnicity of intellectual disability participants were applied during the systematic search.

Intellectual disability is an umbrella term used to describe a range of difficulties and presentations. Within this range are specific syndromes where an intellectual disability diagnosis is viewed as a secondary consequence of the syndrome. A number of these syndromes (e.g. Prader-Willi, Cohen and Bardet-Biedl Syndrome)

are believed to have a genetic influence on obesity, either directly or through behaviour (Harris et.al., 2018). Down's Syndrome is the most common such diagnosis and confers an increased risk of additional health conditions (Mahy et al, 2010). The presence of such diagnoses complicates efforts to live healthier lifestyles. Therefore, studies were only included if participants' primary diagnosis was an intellectual disability, or no other diagnoses known to co-occur with an intellectual disability were described.

Specific to age, once a person with an intellectual disability reaches adulthood, particularly where they are accommodated in a care environment, it is unusual for them to experience the transitions their non-disabled peers encounter (e.g. moving for education, work or retirement). Consequently, people with an intellectual disability may remain in the same residence for the majority of their adult life. The result is that a study's approach to sampling is more likely to recruit participants across a number of age brackets (Spassiani et al., 2019). People with an intellectual disability also appear to age faster than non-disabled adults and experience age-related chronic conditions from as early as 30 years old (Jurkowski et al., 2009; Spassiani et al., 2019). Therefore, it was decided to include studies with adult participants from 18 years old with no upper age limit.

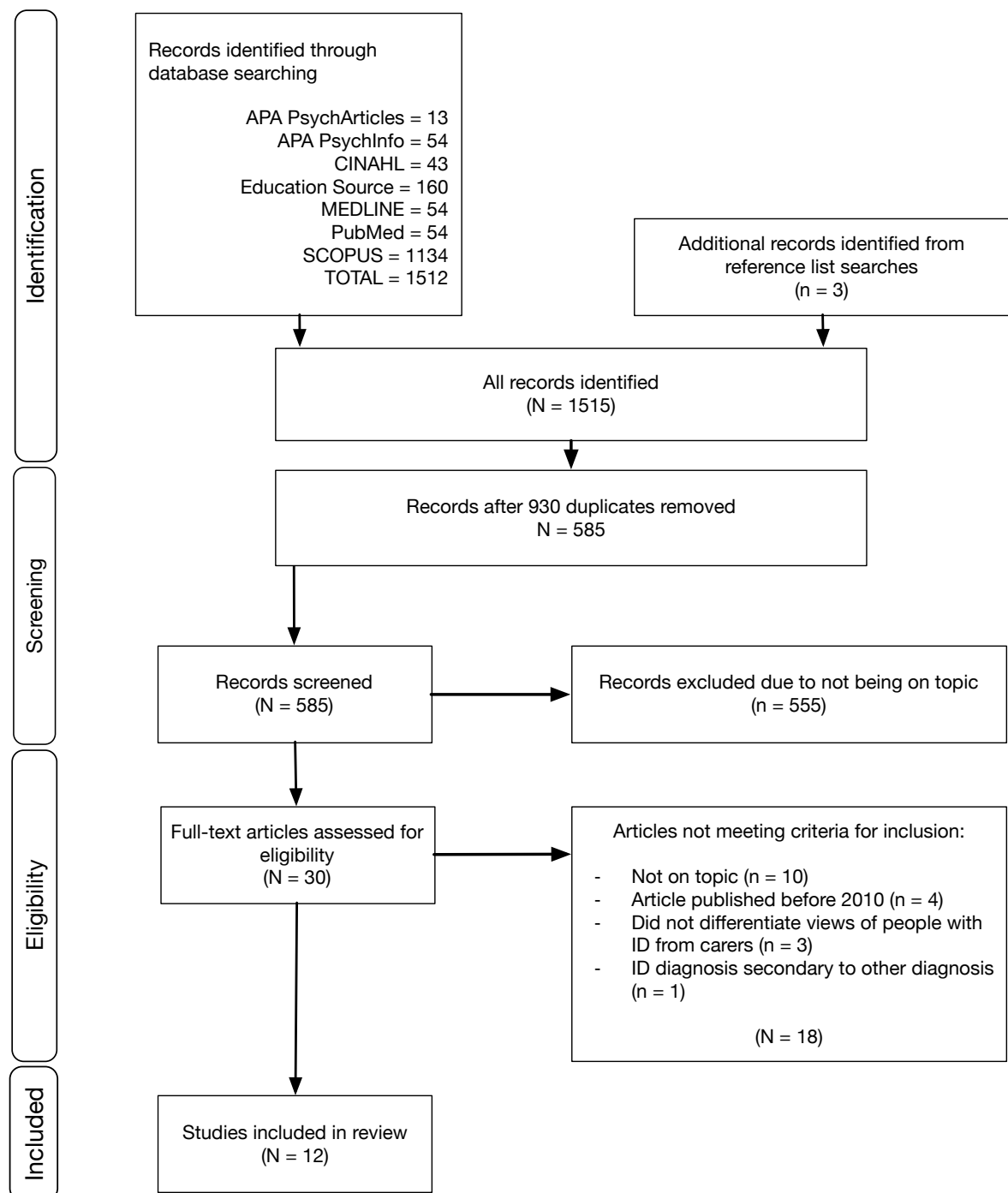
There is a growing body of literature describing health promotion interventions adapted to or specifically designed for people with an intellectual disability. Studies that explored how people with an intellectual disability experienced health promotion programmes, or the management of specific health conditions, were excluded on the basis that they referred to the experience of the specific program or health condition rather than attempts to live a healthier lifestyle in general. Lastly, it is common for interviews, focus groups and other methods of collecting qualitative data from people with an intellectual disability to include active communication support by, or the accompanying views of carers. The inclusion of carers provides additional details regarding the context of experiences shared by people with an intellectual disability. However, the views of carers normally vary from those of the person with an intellectual disability they support. To be included studies had to clearly differentiate

and detail the contributions of participants with an intellectual disability from those of carers.

While healthy lifestyle advice has been a growing public health priority since 1986 (WHO, 2009), it is only in the decade preceding this review that concerted action has become an international concern. In 2009 Change 4 Life was launched in the UK, a national program aimed at implementing the Healthy Weight, Healthy Lives (Department of Health, 2008) strategy intended to tackle rising levels of obesity among children and adults. In 2011 the United Nations (UN) held its first high level meeting on the social determinants of health and the impact of non-communicable diseases (NCDs) that result from poor diet, low levels of physical activity, smoking and the excess consumption of alcohol (OECD, 2019). To reflect this change in national and international priorities the current review excluded papers published before 2010.

Classification of Studies

Figure 1.1: PRISMA flow diagram detailing study selection process



The steps taken to identify returned studies that met inclusion criteria are detailed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram, illustrated in figure 1.1 (Moher et.al., 2009).

In total 1509 studies were identified through the database searches. After removal of 927 duplicates the titles and abstracts of 585 studies were screened in relation to the described inclusion and exclusion criteria (table 1.2). This led to the removal of a further 555 studies. The full texts of the remaining 30 studies were reviewed and their references screened for additional studies not returned by the database searches. A further 3 studies were identified in this manner. Of these 33 studies a further 21 were excluded. This was due to date of publication, that the views of people with an ID were not discernible from the views of others, that the study focused on an intervention or programme, or the intellectual disability diagnosis was secondary to a primary condition (e.g. Down's Syndrome). Upon completion of the systematic search 12 studies were retained and subjected to a systematic review.

Quality Assessment Checks

The retained 12 studies were assessed for quality using the Critical Appraisal Skills Program (CASP, 2018) checklist for qualitative studies (Appendix 1.2). The CASP is the most commonly used quality appraisal tool in health and social care related qualitative literature reviews. It has also been endorsed by the Cochrane Qualitative and Implementation Methods Group, and the WHO for use in systematic reviews of qualitative research (Long, French & Brooks, 2020). The tool assesses a study against 10 criteria, with a score allocated on the degree to which each is met based on what is reported (fully met is denoted by a 'yes' and scores 2; unsure is denoted by 'can't tell' and scores 1; and not met by a 'no' with a score of 0) (CASP, 2018). Scoring is guided by a set of "hints" for each criterion. Papers can receive a score between 0 and 20, with a midpoint of 10. Papers that score below 10 may be considered for removal on the basis of quality. However, the decision to exclude a study based on a low CASP score includes consideration of the tools limitations. The main limitation is its assessment of a paper based on the published information. Journals place restrictions on authors concerning presentation and word count. Papers may be unfairly penalised due to these restrictions that do not reflect the quality of the study's methodology (Purssell, 2020).

The included papers were also rated for quality by a second researcher not involved in this review. Cohen's Kappa (K) was performed to determine the level of agreement between the author and the independent rater. The initial overall Kappa score was .459, suggesting moderate agreement (McHugh, 2012). Where the quality ratings differed the author and the second researcher discussed these differences. Comparison revealed that the majority of disagreement centred on questions 3, 6 and 8 of the CASP tool. The author and second researcher discussed their respective ratings, and where agreement was reached quality rating scores were adjusted. The final overall Kappa was .789, suggesting substantial agreement (McHugh, 2012). Full details of both raters final CASP scores and Kappa statistics can be found in Appendix 1.5.

The quality rating scores for each study are included as percentages, alongside the inter-rater reliability Kappa statistic, in table 1.3. All studies received CASP quality assessment scores between 13 and 19. Studies often received a lower quality score due to a lack of information justifying the chosen research method or the researcher's relationship to participants and the phenomenon of interest. However, this information may not have been included to satisfy journal restrictions on word count.

Characteristics of Studies

Table 1.3 overleaf summarises the key characteristics of each included study.

Table 1.3 Summary characteristics of Included Studies

Authors, Date, Country	Aim(s)	Sampling Approach	Sample	Data Collection	Main Findings
Quality Rating (CASP)				Data Analysis	
Inter-rater Reliability Kappa statistic (K)					
<p>Vlot-van Anrooij et al., 2020 * **</p> <p>Netherlands</p> <p>CASP=95%</p> <p>K=1.00</p>	<p>To explore what assets for physical activity and healthy nutrition do people with moderate intellectual disabilities and proxy informants of people with severe/profound intellectual disabilities identify and prioritise.</p>	<p>Purposive sampling to recruit participants with moderate ID and proxies for people with severe or profound ID.</p>	<p>51 participants in total.</p> <p>21 people with moderate ID split into 4 groups, aged between 21 and 69 years old.</p> <p>30 carers as proxy informants for people with severe or profound ID, aged between 7 and 83 years old.</p> <p>Proxies had known the person with ID for at least 6 months and had weekly contact with them.</p>	<p>Data Collection: Nominal Group Technique (NGT), a mixed-method approach used to explore opinion on a given topic through semi-structured group discussions. Group discussions were audio recorded.</p> <p>Data Analysis: Thematic content analysis. Statistical analysis was performed on the ranking of ideas.</p>	<p>3 themes and 14 sub themes are described.</p> <p>The theme 'People' included 5 sub themes – encouraging support, supportive network, confidence building support, values about being healthy and an open conversation. The theme 'People' focused on how the social network can support healthy living</p> <p>The theme 'Places' included 5 sub themes – healthy home environment, engaging environment, accessibility, tailored environment and homely environment. The theme 'Places' referenced the tools, facilities, person-environment fit and accessibility that influence healthy living behaviours.</p> <p>The theme 'Preconditions' included 4 sub themes – healthcare and prevention, financial aspects, health-promoting organisational policies and opportunities to engage. The theme 'Preconditions' related to healthcare and prevention, financial resources, organisational/systemic health promotion priorities and activities.</p> <p>Practical, visible and concrete aspects of support were ranked higher by people with an ID, while proxy participants referenced more abstract aspects and preconditions for support.</p>

					Participants with an ID described more ideas related to the theme of 'Places', while proxy participants described more ideas related to the theme of 'People'. Both groups described roughly equal numbers of ideas related to 'Preconditions'.
Caton et al., 2012 England CASP=80% K=.808	To explore what people with ID understand being healthy to mean and what their experiences are of healthy lifestyles.	Purposive sampling, combined snowball sampling. Participants recruited from existing ID self-advocacy and expert by experience groups.	13 adult participants with ID, 6 women and 7 men. Ages ranged from 27 to 72 years old. Mean 51.5 (SD=12.03). 12 participants communicated verbally during the interviews and one used a speech-generating device (SGD). No new words were programmed into the SGD for the interview.	Data Collection: Semi-structured interviews. Data Analysis: Thematic analysis.	5 themes are described: <ul style="list-style-type: none"> - Diet (with 1 sub theme - moderation) - Physical activity and exercise - Medication - Smoking and alcohol (with 1 sub theme - moderation) - Well-being - Barriers to healthy living (with 6 sub themes - inadequate support and opportunity, perception of risk, stress and stressful situations, transport; mood, motivation and preference, and ageing) - Facilitators to healthy living (with 2 sub themes – support from carers and illness) Participants demonstrated: <ul style="list-style-type: none"> - understanding of what it means to be healthy, have a healthy diet, the dangers of substance misuse, and the benefits of exercise. - some knowledge about rationales for engaging in healthy behaviours.

<p>Kuijken et al., 2016 *</p> <p>Netherlands</p> <p>CASP=80%</p> <p>K=.778</p>	<p>To gain insight into the perspectives of people with mild to moderate ID on healthy living.</p>	<p>Both purposive sampling and snowball sampling were used.</p> <p>Participants were recruited from three regional expertise centres providing support to people with ID.</p>	<p>21 adult participants with mild to moderate ID, 9 women and 12 men.</p> <p>Ages ranged from 19 to 65 years old.</p>	<p>Data Collection: Semi-structured focus groups.</p> <p>Data Analysis: Domain analysis and thematic analysis.</p>	<p>Findings were organised in relation to two overarching themes defined by the research question.</p> <p>The first theme, perceptions of own health, included 3 sub themes:</p> <ul style="list-style-type: none"> - what is healthy for you individually - knowledge of what is healthy/unhealthy - feeling healthy <p>Feeling healthy was further subdivided into 4 sub themes:</p> <ul style="list-style-type: none"> - the perception of your own health - happiness - feeling the need to do something (un)healthy - level of independence <p>The second theme, factors experienced to relate to the ability to live healthy, included 5 sub themes specifically referencing resources in the social environment:</p> <ul style="list-style-type: none"> - motivate or stimulate person with ID to live healthily - invite people with ID to live healthily - support or help people with ID to live healthily - provide information to people with ID to live healthily - monitor the lifestyles of people with ID <p>The remaining sub themes included:</p> <ul style="list-style-type: none"> - Motivation
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					- Resources in the physical environment (health
<p>Leser et al., 2018 **</p> <p>USA</p> <p>CASP=75%</p> <p>K=.1.00</p>	<p>To qualitatively explore how adults with an ID, those responsible for ID support services, carers and family members define "health" for people with ID, as well as how they perceive the role of formal carers in promoting the health of people with ID.</p> <p>To understand the barriers to health promotion for people with ID and the ways to overcome these barriers.</p>	<p>Both purposive and convenience sampling were used.</p> <p>Participants were recruited via e-mail and posters displayed by local disability organisations.</p>	<p>48 participants in total.</p> <p>6 adults with an ID diagnosis. Mean age=69.3 (SD=3).</p> <p>10 agency administrators, Mean age=50.9 (SD=11).</p> <p>17 family members. Mean age=50.8 (SD=14).</p> <p>15 DSPs Mean age=43.6 (SD=13).</p>	<p>Data Collection: Semi-structured focus groups.</p> <p>1 focus group with adults with ID.</p> <p>1 focus group with agency administrators.</p> <p>2 focus groups with family members.</p> <p>2 focus groups with DSPs.</p> <p>Data Analysis: Grounded Theory.</p>	<p>7 themes are described:</p> <ul style="list-style-type: none"> - What being healthy means for people with ID (with 3 sub themes – practicing healthy behaviours, having autonomy and mental/emotional well-being) - The role of DSPs in health promotion (with 3 sub themes – basic role, different interpretations of role in relation to health and providing social interactions) - Barriers to health promotion at individual level for person with ID (with 5 sub themes – basic rights/preferences, fear, interpretation of rights of people with ID, limited income, and limitations pertaining to specific disabilities) - Barriers to health promotion at individual level for DSP (with 2 sub themes – motivation and DSPs rights) - Barriers to health promotion at interpersonal level between DSPs and people with ID receiving support (with 3 sub themes – role-modelling, power dynamic and rewards) - Barriers to health promotion at organisational level pertaining to field of direct care (with 3 sub themes – turnover, unenforceable policies, and training) - Strategies for overcoming barriers to health promotion (with 6 sub themes – individualised service plan, trainings, indirect role-modelling, direct role-modelling, make small changes, and directly teach/show healthy foods)

<p>Salomon et al., 2019 *</p> <p>Australia</p> <p>CASP=65%</p> <p>K=.839</p>	<p>This study explored barriers and enablers of healthy eating and physical activity, and the impact of ageing on physical activity and eating practices from the perspectives of older people with intellectual disabilities and their paid support workers.</p>	<p>Purposive sampling was used.</p> <p>Participants with ID were recruited from a variety of carer settings – disability group homes, family, nursing homes and those living independently.</p> <p>Carers were recruited from day care or residential services providing support to people with mild to moderate ID diagnoses.</p>	<p>14 participants in total. 8 people with mild to moderate ID diagnoses (1 woman, 7 men), and 6 paid carers.</p> <p>Participants with ID were 60 years old.</p> <p>Carers were aged 21 years or older.</p>	<p>Data Collection: Semi-structured focus groups, two with people with ID and one for carers.</p> <p>Data Analysis: Focus groups were recorded, transcribed and analysed thematically using the predefined categories of barriers to physical activity; enablers of physical activity; barriers of healthy eating; and barriers of healthy eating.</p>	<p>Findings were organised in relation to the identified barriers and facilitators of physical activity and healthy eating.</p> <p>4 themes were identified as barriers to physical activity by both people with an ID and support workers:</p> <ul style="list-style-type: none"> - Ageing - Health problems - Environmental barriers - Resource-related barriers <p>3 themes were identified as facilitators of physical activity by both people with an ID and support workers:</p> <ul style="list-style-type: none"> - Incorporating physical activity into everyday routines - Having choices - rewards <p>3 themes were identified as barriers to physical activity by support workers:</p> <ul style="list-style-type: none"> - Lack of resources - Poor health literacy and message inconsistency - Lack of client motivation to choose healthy foods <p>1 theme was identified as facilitator of physical activity by both people with an ID and support workers:</p> <ul style="list-style-type: none"> - Visual teaching aids
<p>van Schijndel-Speet et al., 2014 *</p> <p>Netherlands</p>	<p>To explore the preferences of older adults with ID for specific physical</p>	<p>Purposive and opportunity sampling were used.</p>	<p>40 participants with mild to moderate ID in total.</p>	<p>Data Collection: Fourteen in-depth interviews and four</p>	<p>Findings were organised in relation to the identified barriers and facilitators of physical activity.</p>

<p>CASP=80%</p> <p>K=.630</p>	<p>activities, and to gain insight into facilitators and barriers to engaging into physical activity.</p>	<p>Participants were recruited from attendees at 7 day activity centres provided by 3 different care agencies.</p>	<p>The average age of participants who participated in individual interviews and focus groups was 60.6 and 61.5 years-old, respectively.</p> <p>Individual ages ranged between 50 and 80 years-old.</p> <p>5 men and 9 women participated in individual interviews. 9 men and 17 women participated in one of four focus groups.</p>	<p>focus groups were undertaken.</p> <p>Data Analysis: Thematic analysis.</p>	<p>Facilitators were grouped within 2 themes, each with sub themes:</p> <ul style="list-style-type: none"> - Psychological factors (with 6 sub themes – enjoy activity, body feels good and flexible, relaxed and gives energy, good for health, useful activity and familiarity/routine) - Social and cultural factors (with 5 sub themes – staff/family support physical activity, pleasant atmosphere, activity with others, reward and status of activity) <p>Barriers were grouped within 4 themes, each with sub themes:</p> <ul style="list-style-type: none"> - Personal factors (with 6 sub themes – being tired quickly, physical discomfort, physical limitations, pain, dependence on staff and road safety) - Psychological factors (with 7 sub themes – dislike activity, fear of falling, dislike feeling tired, too difficult, useless activity, retirement and relaxation, and feeling insecure in social context) - Social and cultural factors (with the sub theme staff members inhibit physical activity) - Physical environment factors (with 5 sub themes – bad weather, transfer, money, transportation and lack of staff time)
<p>Brooker et al., 2015 *</p> <p>Australia</p>	<p>To better understand how physical activity programs may</p>	<p>Purposive sampling was used to recruit participants with an ID</p>	<p>11 participants in total.</p>	<p>Data Collection: Semi-structured interviews.</p>	<p>3 themes are described:</p> <ul style="list-style-type: none"> - Individual factors that generally facilitated activity

<p>CASP=80%</p> <p>K=.808</p>	<p>contribute to improved health and social-support outcomes for people with ID.</p>	<p>from a supported employment scheme.</p> <p>Volunteer support workers at the scheme were recruited using the organisations networks.</p>	<p>5 people with ID, 4 women and 1 man aged between 30 and 59 years old. ID participants lived independently, in supported accommodation, group homes or with family.</p> <p>6 volunteers, 5 women and 1 man aged between 20 and 39 years old. Volunteers were university students, social workers or support workers.</p>	<p>Two volunteers were interviewed together; all other volunteers were interviewed individually.</p> <p>Data Analysis: Thematic analysis.</p>	<ul style="list-style-type: none"> - External factors that posed barriers to participation - Broader normative factors that directed participation <p>A key reflection arising out of the thematic analysis was that participants with intellectual disability and volunteers highlighted subtle but pervasive differences in barriers and facilitators to being active.</p>
<p>Dixon-Ibarra et al., 2016 *</p> <p>USA</p> <p>CASP=80%</p> <p>K=.600</p>	<p>To qualitatively examine physical activity within the group home setting where people with an ID reside.</p>	<p>Purposive sampling. Participants were recruited from three group home agencies in the western United States that provide 24 hour support for residents with ID.</p>	<p>20 participants in total.</p> <p>6 adults with ID, 5 men and 1 woman aged between 26 and 65 years old.</p> <p>8 carers, 2 men and 6 woman aged between 20 and 28 years old.</p> <p>6 group home managers, 2 men and 4</p>	<p>Data Collection: Semi-structured interviews.</p> <p>Data Analysis: Thematic analysis.</p>	<p>6 themes are described:</p> <ul style="list-style-type: none"> - Nature of residents' physical activity (with 6 sub themes – types of physical activity, active occupation, sedentary occupation, community options, frequency of physical activity, and sedentary behaviours) - Barriers to physical activity (with 10 sub themes – resident motivation, resident level of intellectual functioning, busy schedules, limited staff, negative support, resident physical limitations, resident age, cost, weather, staff and resident resistance to change)

			woman aged between 20 and 54 years old.		<ul style="list-style-type: none"> - Facilitators to physical activity (with 9 sub themes – role modelling/positive encouragement, social engagement, self-determined physical activity, reducing negative behaviours, winning, enjoyment, having a house pet, health, and practice sport) - Personal factors (with 5 sub themes – attitudes, knowledge, expectations, intention, and self-efficacy) - Operational factors (with 9 sub themes – daily operations, busy schedules, routine schedules, organisational priorities, self-advocating, staff training, staff turnover, limited staff, and job experience) - Solutions to increase physical activity (with 8 sub themes – resident and staff buy-in, make it fun, address diverse needs, self-determination, simplicity, engrained into the system, incentive program, and physical activity volunteers)
<p>Taliaferro & Hammond, 2016 *</p> <p>USA</p> <p>CASP=70%</p> <p>K=.643</p>	To identify the barriers, facilitators, and needs influencing physical activity participation of adults with ID.	Purposive sampling. Participants were recruited from 14 organisations providing support to people with ID. Participants self-selected by replying to recruitment letters.	<p>12 participants in total.</p> <p>6 adults with ID, 3 men and 3 women aged between 23 and 38 years old.</p> <p>ID participants lived either independently, in a community-based setting or with family. One participated reported having an</p>	<p>Data Collection: A combination of surveys and semi-structured focus groups.</p> <p>Data Analysis: A directed approach to qualitative content analysis was used.</p>	<p>Findings were organised in relation to the identified barriers and facilitators of physical activity.</p> <p>Facilitators were grouped within 5 themes, each with sub themes:</p> <ul style="list-style-type: none"> - Individual constraints (with 4 sub themes – motivation and skills, reliance on others, personal health/safety, and time/work constraints) - External influences (with 3 sub themes – caregiver considerations, safety limitations, and imposed choice of activity)

			<p>additional physical disability.</p> <p>6 carers, Mothers of participants with ID, aged between 40 and 70 years old.</p>		<ul style="list-style-type: none"> - Organisational barriers (with 4 sub themes – resource issues, information dissemination, policies, and ease of access) - Facilitators of physical activity (with 2 sub themes – primary caregivers as champions of physical activity, and camaraderie) - Needs and ideals (with 3 sub themes – family program involvement, improved programmatic structure, and programmatic support)
<p>Doherty et al., 2018 *</p> <p>England</p> <p>CASP=85%</p> <p>K=.737</p>	<p>To explore the views and experiences of adults with ID in relation to barriers and facilitators to eating well, living well and weight management.</p>	<p>Purposive sampling. Participants were recruited through a self-advocacy group for adults with an ID diagnosis.</p>	<p>27 participants in total.</p> <p>19 adults (13 men, 6 women) with an ID, supported by 8 carers.</p> <p>Age of ppl with ID 32-57 years (of the 13 ppl with ID who shared their age).</p>	<p>Data Collection: Semi-structured focus groups facilitated by skilled facilitators, a questionnaire and worksheet. Each group was recorded and transcribed.</p> <p>Data Analysis: Thematic analysis.</p>	<p>6 themes are described:</p> <ul style="list-style-type: none"> - Caring support - Group support - Better, clearer, accessible information and training - Money - Recognition of health and weight concerns by self and others - External barriers <p>Barriers included restricted personal finances, low/lack of carer knowledge and skills, lack of accessible information, inaccessible services and community resources, and societal barriers (e.g. widespread advertising of junk foods).</p> <p>Participants expressed frustration in relation to these barriers to living well, eating well and managing their weight, if this is what they want.</p> <p>Participants suggested facilitators including clear accessible information about healthy lifestyles, reasonable</p>

					adjustments to services, additional training, buddy support schemes and working together to improve services.
Gee et al., 2020 ** New Zealand CASP=75% K=.800	To investigate the experiences and patterns of alcohol use amongst individuals with a mild ID living in the community.	Purposive sampling. Participants were recruited through a self-advocacy group. Participants who identified themselves as consumers of alcohol self-selected to take part in the study.	10 adults with ID, Mean age=31.6 (SD=9.6) ranging between 20 and 50 years old.	Data Collection: Semi-structured interviews. Data analysis: Braun and Clarke's approach to thematic analysis.	2 themes are described: The theme "Drinking Patterns" recognised a low level of alcohol consumption amongst the participants. The theme "Influences on Drinking Behaviour" demonstrated the importance of their social network on promoting and reinforcing low levels of alcohol consumption as well as the influence of television and advertising.
Kerr et al., 2017 * Scotland CASP=75% K=.804	To gain an understanding of the tobacco and alcohol-related health promotion needs of adults with ID.	Purposive sampling was used to recruit people with intellectual disabilities, family carers and health and social care professionals (HSCPs).	33 participants in total. 16 people with ID, 12 men and 4 women, average age of 38 years, ranging between 18 and 64 years. 2 family carers, 15 health and social care professionals, 2 men and 13 women, average age of 44 years old, ranging between 27 and 58 years.	Data Collection: Semi-structured focus groups. Data Analysis: Data was analysed based on framework analysis, with social cognitive theory providing the initial structure for arranging identified themes.	4 themes are described: <ul style="list-style-type: none"> - Being like others - Social and emotional influences - Understandings, misunderstandings and learning from experience - Choices and challenges Reasons for smoking and drinking alcohol echoed those of the general population; however, health promotion needs were more complex (e.g. linked to problems with consequential thinking, as well as low levels of self-efficacy).

* Studies that did not provide information regarding the mean age of participants or the standard deviation (SD) of the mean age.

** Studies that did not provide information regarding the gender of participants.

Strengths and Limitations of Included Studies

The included studies shared a number of strengths, with all collecting data directly from people with an intellectual disability. Three studies employed an inclusive approach that ranged from consulting people with an intellectual disability on the research question and interview schedule (Caton et al., 2012; Doherty et al., 2018; Vlot-van Anrooij et al., 2020), developing information sheets and recruiting participants (Doherty et al., 2018; Vlot-van Anrooij et al., 2020), to the involvement of people with an intellectual disability as co-researchers (Vlot-van Anrooij et al., 2020).

The majority of included studies did not publish information on the severity of participants' intellectual disability diagnoses (Brooker et al., 2015; Caton et al., 2012; Dixon-Ibarra et al., 2016; Doherty et al., 2018; Gee et al., 2020; Kerr et al., 2017; Leser et al., 2018; Taliaferro & Hammond, 2016). Of the studies that did provide this information participants had received either a mild or moderate diagnosis (Kuijken et al., 2016; Salomon et al., 2019; van Schijndel-Speet et al., 2014; Vlot-van Anrooij et al., 2020). A common limitation of qualitative research with this group is that participation often relies on the ability to communicate in spoken or written language. For this reason people who have received a mild or moderate intellectual disability diagnosis tend to be overrepresented in the qualitative literature (Caton et al., 2012). It can therefore be assumed that the findings of included studies and this review overall are limited to people with a mild or moderate intellectual disability.

To accommodate the range of participants' communication abilities a number of approaches to increasing accessibility were described by several studies. Vlot van Anrooij et al. (2020) and Dixon-Ibarra et al. (2016) translated abstract concepts into concrete terms and increased the time given to participants when discussing them. A number of studies used pictures, videos and visual metaphors (Caton et al., 2012; Kerr et al., 2016; Kuijken et al., 2016). Other studies described using plain English to provide information and ask questions (Brooker et al., 2015; Doherty et al., 2018; Gee et al., 2020; Salomon et al., 2019). While reducing the complexity of the language used and providing additional scaffolding such as pictures is a standard

approach to research with this group, participants' responses may be directed or limited by such scaffolding (Dixon-Ibarra et al., 2016).

The type and degree of demographic and contextual information provided varied across the included studies, limiting the current review's ability to discern the relevance of findings to a specific context or group of people with an intellectual disability. Situating the sample by describing salient characteristics of participants is an important aspect of qualitative research that supports the readers efforts to critically appraise study findings (Ponterotto & Grieger, 2007). A total of 290 people participated across the 12 studies, of which 171 were adults with an intellectual disability with ages ranging between 18 and 80 years old. Biological sex information was available for 80% of the 171 participants with an intellectual disability, with 36% described as female and 44% described as male. Of the 12 included studies 3 were conducted in the Netherlands (Kuijken et al., 2016; van Schijndel-Speet et al., 2014; Vlot van Anrooij et al., 2020), 3 in the United States of America (Dixon-Ibarra et al., 2016; Leser et al., 2018; Taliaferro & Hammond, 2016), 3 in the UK (Caton et al., 2012; Doherty et al., 2018; Kerr et al., 2017), 2 in Australia (Brooker et al., 2015; Salomon et al., 2016) and 1 in New Zealand (Gee et al., 2020). None of the studies provided information regarding participants' ethnicity or details of any co-occurring physical or developmental diagnoses in addition to an intellectual disability. Only one study made specific reference to social deprivation (Caton et al., 2012) as a characteristic of the area from which participants were recruited. Participants' socio-economic status is an important characteristic as it correlates with reduced opportunities to engage in health promoting behaviours and an increased risk of engaging in unhealthy behaviours (Kerr et al., 2017). Though none of the included studies explicitly situated their samples in terms of their socio-economic status, it is reasonable to assume that the level of deprivation encountered by participants varied.

Lower scores were consistently given to all but one of the included studies (Gee et al., 2020) in response to question 6 of the CASP tool. This question concerns the described reflexivity of the researcher and their potential influence on research

findings. Similar to a lack of information that would support situating the sample, the majority of included studies lacked information that would allow the reader to situate the respective researcher. This limits the degree to which each study could be critically examined (Newton et al., 2011).

While some of the included studies developed interpretations based on participant contributions, others approached data analysis using existing theory or the research question as a framework to organise responses (Kerr et al., 2017; Kuijken et al., 2016; Salomon et al., 2019; Taliaferro & Hammond, 2016). This latter approach to analysis introduces the risk that data supporting those theories or questions are over-represented while contextual, unrelated or contradicting information may be less represented or lost (Taliaferro & Hammond, 2016). The author considers it a strength of the current review that both theoretically and contextually driven approaches to analysis were included.

The majority of included studies employed purposive or opportunity sampling. These approaches can increase the risk that participants hold strong views regarding the research question and are more motivated to engage than others (Dixon-Ibarra et al., 2016). Though representativeness is not a goal of qualitative research it is important to hold in mind that findings cannot be generalised to the intellectual disability population. Instead, the included studies and this review are intended to inform discussions and approaches taken to support people with an intellectual disability to live healthier lives where they choose to do so.

Analytic Review Strategy

The 12 included studies were analysed using meta-ethnography, an interpretative approach to qualitative synthesis (Sattar et al, 2021). A specific concern with qualitative syntheses is the potential for the voice of the original participants, and the explanatory context they provide, to become buried beneath layers of interpretation (Atkins et al., 2008). The analytic process of meta-ethnography takes explicit steps

to preserve primary data (Atkins et.al., 2008). Compared to other forms of qualitative synthesis, meta-ethnography can provide both greater detail regarding the analytic process to aid critical appraisal, and a higher order and novel conceptualisation of the phenomenon being studied (Cahill et al., 2018).

There are concerns that meta-ethnography may not be suitable when systematic searches return large numbers of relevant studies (Campbell et al., 2012). The current reviews systematic search returned 12 papers, well within the recommended range for conducting a meta-ethnographic review. Meta-ethnography can also be used to integrate findings from a variety of qualitative methods and philosophical positions (Sattar et al., 2021). The 12 included studies employed 5 separate methods of data analysis, making meta-ethnography an appropriate method of synthesis.

A criticism of health promotion interventions offered to people with an intellectual disability is that they often lack a theoretical basis (Kuijken et al., 2020). Existing health promotion theories were developed in relation to and for the general population (Laverack, 2017). It is not known how well these theories apply to the lives of people with an intellectual disability (Willems et al., 2017). Meta-ethnography, given its analytical rather than descriptive outputs, is often used to support theory development (Sattar et al., 2021). The current review, with its focus on the experiences of people with an intellectual disability as they try to live healthier lives, may provide useful insights to support theory development specific to their context and priorities. For these reasons a meta-ethnographic approach was thought most appropriate.

To ensure best practice this review followed the guidance for conducting a meta-ethnographic synthesis described by Sattar et al. (2021) which provided further detail for completing the 7 stages originally outlined by Noblit and Hare (1988). Each of the 7 stages are described fully in Appendix 1.3. An excerpt from stage 4, determining how the studies are related, is included in Appendix 1.7 to demonstrate how individual studies were analysed and compared. The order of synthesis was

determined based on both the focal aspect of healthy living studies and the CASP quality rating of papers. The included studies varied in which aspect of healthy living they focused on. For the purpose of the analysis studies were first grouped based on their focus (e.g. healthy lifestyle in general, or physical activity, healthy diet, stopping smoking or reducing alcohol specifically). The analysis began with the highest quality papers focused on healthy lifestyle (5 papers), followed by physical activity (4 papers), healthy eating (1 paper), and tobacco and alcohol use (2 papers). This approach prioritised findings from studies categorised as higher quality while preserving findings from studies that also met criteria for inclusion and were categorised as lower quality. No studies were excluded based on their quality rating.

Data was extracted verbatim from the results and discussions sections of each study using the table advised by Sattar and colleagues (see Appendix 1.4 for an example). The table was used to separate the contributions of participants, the interpretations made by the authors and the themes they corresponded to. Included studies were translated into one another by comparing primary and secondary concepts between papers, checking for commonalities or divergence and grouping them accordingly. Groupings were reviewed and translated into one another to form themes. Aspects of the included studies that appeared to disagree were explored. This led to a reciprocal synthesis that generated new themes accounting for the disagreements between studies. Finally, a line of argument synthesis was constructed to illustrate how each of the themes that emerged from the reciprocal synthesis are related.

Findings

Table 1.4 Summary of Superordinate and Subordinate Themes, Cross-Referenced to Related Studies

Superordinate and subordinate theme	Included studies											
	1	2	3	4	5	6	7	8	9	10	11	12
1. In the moment experiences of health-related choices:												
1a. How I feel	•	•	•		•	•	•	•	•	•	•	•
1b. Who I'm with	•	•	•	•				•	•		•	•
1c. Accessibility	•	•	•		•	•		•	•	•		•
2. Factors shaping the environment where health-related choices are made:												
2a. Carers don't know what they should do	•	•		•	•		•	•			•	
2b. If people with an intellectual disability don't feel like being healthy, that's their choice				•	•			•	•		•	
2c. What people with an intellectual disability are told about health		•	•	•	•	•	•		•		•	•

Table 1.4 legend: • Denotes a study that contributed to the adjacent theme. Studies are represented by the following numbers: 1. Vlot van Anrooij et al., 2020; 2. Caton et al., 2012; 3. Kuijken et al., 2016; 4. Leser et al., 2018; 5. Salomon et al., 2019; 6. Van Schijndel-Speet et al., 2014; 7. Brooker et al., 2015; 8. Dixon-Ibarra et al., 2017; 9. Taliaferro & Hammond, 2016; 10. Doherty et al., 2018; 11. Kerr et al., 2016; 12. Gee et al., 2020. Studies are numbered based on the order of synthesis.

Using a meta-ethnographic approach to qualitative synthesis, this study aimed to explore the experiences of people with an intellectual disability as they try to live healthier lives. Following a systematic literature search, 12 studies were identified. Analysis resulted in the development of two interpretative themes, each containing 3

sub-themes, summarised in table 1.4. Theme 1, 'In the moment experiences of health-related choices', details the impact of current or preferred subjective experiences on whether people with an intellectual disability chose health promoting or unhealthy behaviours. Theme 2, 'Factors shaping the environment where health choices are made', highlights the proximal and distal contextual factors that can enhance, direct, or limit health-related choices.

Theme 1. In the moment experiences of health-related choices

Theme 1 presents an insider perspective of people with an intellectual disability as they attempt to live healthier lives. Each included study highlighted the influence of intrapersonal, interpersonal, and environmental factors on decisions to engage in health promoting or unhealthy behaviours.

1a. How I feel

Across 11 studies participants described how they were more likely to engage in activities that were of their choosing (Vlot van Anrooij et al., 2020), "*fun*" (Talieferro & Hammond, 2016, p.126), provided "*social rewards*" (Salomon et al., 2019, p.5) or contributed to their sense of self-efficacy (Dixon-Ibarra et al., 2017).

"...people were more likely to exercise if they had freedom to choose where and when to undertake activities." (Salomon et al., 2019, p.5)

Participant: "I keep the neighbourhood clean. I sweep and I pick up rubbish."

Interviewer: "Do you like to do that?"

Participant: "Nahh like it ... that's not the word. I just want to keep it clean!"

Interviewer: "That's a nice task."

Participant: "Yeah, the oldies like it. They like that I keep their neighbourhood clean." (van Schijndel-Speet et.al., 2014, p.180)

“Residents discussed how they enjoyed physical activity because it was fun. They liked to receive medals, win, travel, practice their sport and be healthy.”
(Dixon-Ibarra et al., 2017, p.6)

While medium and long-term health benefits were described, the majority of participant quotes suggested these benefits were secondary motivators, and sometimes incidental. Instead, what motivated choices were the pleasant emotions and sensations experienced. This was true of both health promoting and unhealthy behaviours.

“I inhale deep into my lungs when I smoke...I think deep inhalation tastes better.” (Kuijken et.al., 2016, p.235)

“Much better [to exercise] with friends”; “[I like exercising] because we do it together.” (Salomon et al., 2019, p.5)

Efforts to avoid or control unpleasant experiences were described where participants anticipated that a health-related activity could result in discomfort, pain or injury.

“When I get tired, I quit the activity.” (van Schijndel-Speet et al., 2014, p.181)

“I used to play cricket and soccer, or play rugby league, but the years went on and it [exercise] just slowly slipped away.” (Salomon et al., 2019, p.3)

“Many adults with ID indicated that certain sports or team activities looked like fun, but a fear of injury, health limitations, or uncertainty of health considerations prevented them from participating...” (Talieferro & Hammond, 2016, p.124)

Perceived self-limitations, could also cause participants to feel emotionally unsafe. In such cases, participants described concerns that they lacked the skills required for an activity, or that unfavourable social comparisons would be made.

“I really would like to cycle again, but I am afraid to fall. And I don’t want to cycle on a stupid tricycle.” (van Schijndel-Speet et al., 2014, p.181)

While the motivation to avoid or control unpleasant states was consistent, the context varied and influenced whether the selected behaviour was a move towards or away from a healthy lifestyle.

“That’s a known fact ... passive smoking is worse for the person that’s breathing it in [from] the person that’s doing the smoking.” (Kerr et al., 2016, p.7)

“... a couple [of friends] said to me ‘You’re a coward if you don’t take a drink’.” (Kerr et al., 2016, p.5)

Similarly, regulating stress, distress or boredom were described as both reasons for and against activities that contributed to a healthier lifestyle.

“...some sort of stressful situation that participants were living in took precedence over any move towards prioritising healthy living.” (Caton et al., 2012, p.255)

“Like I go for a walk if I get a bit cranky and irritable...” (Brooker et al., 2015, p.39)

“Smoking just gives you something to do when you’re bored.” (Kerr et al., 2016, p.6)

1b. Who I'm with

A total of 8 studies described the influence exerted by the behaviours of others on participants efforts to live healthier lives. At times this influence was intentional and towards health promotion.

"What worked for us was a very much hands-on [approach]. We brought...packets of sugar in and then we had the choice of [two different types of breakfast cereal]...and read the "how many sugars in this?" [section] and we filled the cups up with sugar..." (Salomon et al., 2019, p. 7)

At other times, the behaviours of others set an unintentional and inconsistent example. In some cases, the impact was health promoting.

"They don't drink much. I mean my brother used to drink, but he doesn't drink that much...and my sister doesn't really drink at all." (Gee et al., 2020, p.4)

In others, a carers poor health or death served as a cautionary tale, encouraging participants to make healthier choices.

"I didn't drink for a long time because, I don't normally tell a lot of people, and because my {family member} died of alcohol poisoning." (Gee et al., 2020, p.4)

Alternatively, a desire to be like friends or carers, regardless of the impact on health, encouraged unhealthy behaviours.

"There appeared to be a strong desire in some people with intellectual disabilities to mimic the behaviours of their non-disabled counterparts, and in some cases, this meant adopting behaviours such as binge drinking." (Kerr et al., 2016, p.5)

The actions of others could also present inconsistent or unclear messaging about healthy behaviours.

“Sometimes they [carers] bring their lunches from home or they go out and go get something from a restaurant and then bring it back here.” (Leser et al., 2018, p.48)

Carers also played a role in reducing the difficulties participants encountered when trying to live healthier lives. The relational safety participants derived from familiar carers could be just as important as the functional support they offered.

“...adults with (intellectual disability) repeatedly indicated that they received and required support from the caregiver to find (physical activity) opportunities, arrange for their participation, transport them, and provide support during the activity...” (Taliaferro & Hammond, 2016, p.127)

“It’s pretty hard for the clients to make any connections with staff because most people only stay there like three months... Some of the clients in their 40s/50s have been through multiple or hundreds of staff” (Dixon-Ibarra et al., 2017, p.4)

1c. Accessibility

In 9 studies participants described necessary and desired resources for living healthier lives, both at home and in the community.

“...being able to, for example, cook for yourself or eat at home because of good at-home catering...positively influences how healthy they feel... Living close to your work or the swimming pool, so that you can walk or cycle, is highly appreciated by the participants.” (Kuijken et al., 2016, pp.236-237)

“Participants cited the need for better, clearer and more accessible healthy lifestyle information.” (Doherty et al., 2018, p.8)

In each case, challenges accessing those resources were described.

“An overarching theme of frustration emerged...over barriers including restrictions to personal incomes, difficulties obtaining consistent caring support, inaccessible activities and services, external barriers and a lack of clear and accessible information on how to eat well and live well and why this was important.” (Doherty et.al., 2018, pp.9-10)

Limited financial and related resources further restricted participants' access.

“...transportation entailed costs that most of the older adults could not afford. Lack of money sometimes forced older adults to stop an activity they enjoyed...” (van Schijndel-Speet et al., 2014, p.181)

In addition, people with an intellectual disability framed carers as a collective environmental, and sometimes scarce resource.

“You have to be patient. Staff members never have time to walk with you, to go outside. They always write and sit in their office.” (van Schijndel-Speet et al., 2014, p.181)

“Sometimes (carers) don't want to take you nowhere.” (Leser et.al., 2018, p.48)

“...participants referred to organisational and external issues impacting upon the opportunity they had to engage in healthy lifestyle choices. These included that staff change their shifts a lot...limited staff cooking skills...” (Caton et al., 2012, p.254)

Theme 2. Factors shaping the environment where health-related choices are made

Though the focus of this review is on people with an intellectual disability, their experiences were significantly affected by and connected to the experiences of carers. Theme 2 summarises an outsider perspective held by carers, and how it influenced participants efforts to live healthier lives.

2a. Carers don't know what they should do

In 7 studies carers were described as “*time poor*” (Salomon et al., 2019, p.5), under resourced, insufficiently trained and lacking clear direction concerning how best to support participants to live healthier lives.

“...staff were unable to describe types of activities that certain residents (i.e., those with a physical disability or who were ageing) could be doing and did not know how much the residents should be pursuing.” (Dixon-Ibarra et al., 2017, p.6)

“They're in my office daily saying, “I wish I could help her. I wish I could convince her. I wish I could get him to make these different choices. I don't know how.” (Leser et al., 2018, p.50)

Carers perceived multiple duties within their role. However, where and when health promotion should and could be incorporated was not clear.

“In general, participants viewed the basic responsibility of (carers) as keeping those they support...safe...” (Leser et.al., 2018, p.44)

“Your job is to provide them with information, education, show them some things that can help them...” (Leser et al., 2018, p.45)

“...priorities...included getting the residents involved in the community, providing social opportunities, having relaxation time, and addressing doctor orders.” (Dixon-Ibarra et al., 2017, p.7)

Even when opportunities to support healthier lifestyles were clear, carers highlighted how limited financial, logistical and organisational resources reduced the feasibility of doing so.

“...they are on a fixed income, which definitely takes away their ability to eat a balanced diet.” (Leser et al., 2018, p.46)

“Participants also felt that carers...required training so they could better support people with intellectual disabilities to eat well, live well and manage their weight.” (Doherty et.al., 2018, p.8)

“Limited human and educational resources were highlighted as a barrier to providing healthy eating support.” (Salomon et al., 2019, p.5)

Carers often described feeling that they were responsible for “activating” (Vlot van Anrooij et al., 2020, p.6) participants health behaviours without the means or knowledge to do so.

“...sometimes clients were provided with incorrect information about healthy eating by staff...” (Salomon et.al., 2019, p.6)

“So that’s the concern for me. It’s that what we are modelling and dictating, we have way too much power to not regulate this better, but I don’t know how...” (Leser et al., 2018, p.49)

These factors tended to combine in ways that left some carers feeling there were contradicting expectations of their role - a perceived trilemma between promoting health, preventing harm, or protecting rights.

“Some participants thought that (carers) should actively make choices for the person they support, while others thought that making healthy or unhealthy behavioural choices should be left to the person...” (Leser et al., 2018, p.44)

When a person with an intellectual disability chose to engage in unhealthy behaviours, some carers expressed a fear that they would be in the wrong regardless of what they did.

“If you are even borderline taking somebody’s rights away, you are on the abuser registry...” (Leser et al., 2018, p.46)

2b. If people with an intellectual disability don’t feel like being healthy, that’s their choice

The authors of 5 studies described how the trilemma was sometimes resolved by prioritising autonomy or risk reduction.

“Several comments were made by participants with (intellectual disability) concerning what they were and were not allowed to do or participate in as told by their (carer) or doctors...” (Taliaferro & Hammond, 2016, p.125)

“Several participants noted that (carers) may want to help people make healthy choices, but that, ultimately, the choice to make healthy decisions has to be left to the person...” (Leser et al, 2018, p.48)

The perspective of carers, due to the limited resources at their disposal and their own efforts to make sense of how health promotion factored into their role, influenced how this choice was rationalised.

“...carers appear to have a limited awareness of potential barriers to lifestyle changes...they more readily identify intrapersonal barriers...than interpersonal and external barriers to change.” (Caton et.al., 2012, p.256)

“Support workers...described factors such as poor concentration and challenging behaviours as negatively impacting the person’s ability to take part in physical activity.” (Salomon et.al., 2019, p.4)

“The most described barrier to physical activity...was the residents’ lack of motivation. (Carers) believed that residents would rather be inactive.” (Dixon-Ibarra et.al., 2017, p.5)

Carers’ ability to promote health was further affected by inconsistent approaches to behaviour support.

“Inadequate staffing ratios and lack of education contributed to support workers using “junk” food to contain or de-escalate challenging behaviours.” (Salomon et.al., 2019, p.6)

“I think that a lot of times in the field, in general, that people tend to offer things like soda or fast food as a reward or to appease people.” (Leser et.al., 2018, p.49)

2c. What people with an intellectual disability are told about health

Across 9 studies authors differed in their interpretations of the health knowledge held by participants. While some asserted that responses indicated a good understanding of health, health behaviours and their associated outcomes, others thought responses lacked depth.

“...mentioned by many participants was their ability to distinguish between healthy and unhealthy behaviours and then making a choice to moderate unhealthy behaviour.” (Caton et.al., 2012, p.254)

Across studies the quality and depth of health knowledge held by participants appeared to be comparable and suggested that received health information may not have been fully understood or retained.

“Beer is bad for your health, isn’t it?...It kills you.” (Caton et al., 2012, p.253)

“...participants talked about the benefits...of eating and drinking healthily. Often these benefits were couched in vague terms of being “good for you.” (Caton et al., 2012, p.252)

“...findings demonstrate that many people with intellectual disabilities have a superficial understanding of the health-related consequences of smoking and drinking excessively...” (Kerr et.al., 2016, p.11)

Between studies, participants concern for their safety during physical activity and meal preparation was contrasted by a lack of concern regarding the consequences of drinking alcohol.

“I get asthma ... [so] I stopped walking to work.” (Salomon et.al., 2019, p.4)

“I need some supervision...because of the stove, I wanted to make tea one time...I was checking if the stove was on and then I burnt myself...” (Kuijken et.al., 2016, p.236)

“While they freely discussed the social side of drinking and the short-term consequences of drinking excessively, little was said or apparently understood... about the medium and long-term health-related consequences of drinking too much.” (Kerr et.al., 2016, p.9)

It was noted in several studies that health knowledge and associated intentions did not equate to health promoting action.

“...when they have to translate these concepts into behaviours, they face several difficulties...merely knowing what is (un)healthy is not sufficient to be able to live healthily.” (Kuijken et.al., 2016, pp.238)

Combined, the studies suggest a distinction between participants general knowledge about health and knowledge of how to apply it to living healthier lives.

“... the point is you must either get an appetizer or a dessert, so you get sufficient nutrients.” (Kuijken et al., 2016, p.232)

Discussion

This study employed a meta-ethnographic approach to qualitative literature synthesis. The aim was to explore how people with and intellectual disability experience trying to live healthier lives. A systematic search identified 12 studies, analysis of which led to the development of two interpretative themes. These themes summarised a reciprocal synthesis of an insider perspective held by participants with an intellectual disability, and an outsider perspective held by their carers regarding efforts to live and promote healthier lives. In this section the interactions between these perspectives, and how they facilitate or impede efforts to live healthier lives, are described within a line of argument synthesis (Sattar et al., 2021).

Line of Argument Synthesis

A key finding of this review is that health benefits were often not at the forefront of participants' minds when making health-related choices. Instead, their decisions were based on how they expected to feel (emotionally and/or physically), which itself depended on the nature of the choice and the interpersonal and environmental context in which it was made.

Behavioural research is clear that people who adopt and maintain healthy behaviours do so because those behaviours have become habitual (Wood & Neal, 2016). Habits form when a behaviour is consistently rewarded. This review indicates that what people with an intellectual disability find most rewarding about healthy behaviours include opportunities to experience social and intrinsic rewards.

How people with an intellectual disability felt was closely related to who they were with. The included studies presented two ways in which others, typically carers, could influence the efforts of participants to live healthier lives. Intentional promotion of healthier choices tended to present options in concrete, explicit terms by integrating them into normal daily choices. These intentional efforts were often described to be successful in their aim. Alternatively, actions that were not intended

to, but nevertheless influenced participants health-related choices, could move them both towards and away from a healthier lifestyle. This appeared to have a secondary consequence of presenting participants with an unclear, and even contradictory picture of what a healthier lifestyle meant in the context of their daily life. Crucially, whether either form of influence led to choices that were consistent with healthier lives depended on how they affected the in the moment subjective experiences of participants. Participants also described how the accessibility of resources for living healthier lives, including the availability of carers, affected how they felt. The more accessible resources were, or the easier it was for participants to be independent, the less likely they were to perceive unpleasant self-limitations. Conversely, the more barriers they encountered, in physical, social, or emotional terms, the more likely participants were to experience discomfort or distress.

Where accessibility was a consistent problem, participants were more likely to avoid the associated activities and the unpleasant sensations that accompanied failed attempts. This is consistent with the literature describing learned helplessness, a self-regulation strategy that may be used when a person perceives no control over an unpleasant consequence that is likely to occur (Winterflood & Climie, 2020). A consistent experience of unpleasant outcomes beyond a person's control can understandably reduce their motivation to engage in the associated behaviours (Mohanty et al., 2015). In turn, this can result in a negative cycle of reducing motivation, low mood and low self-efficacy (Winterflood & Climie, 2020). In relation to a healthier lifestyle, the included studies described a range of accessibility barriers concerning financial, tangible and social resources.

How carers understood their role in promoting health, and how they made sense of health-related choices, influenced the support they offered. None of the included studies identified a clear definition of a healthy lifestyle that had been provided to carers. Similarly, no studies described efforts by care providers to define health, a healthy lifestyle or how to support the individual with an intellectual disability to achieve and maintain health in their daily life. In the absence of such guidance carers developed their own definitions for health that informed their efforts to

promote it. However, these definitions often lacked coherence, leading to inconsistent and sometimes contradictory attempts to support participants to live healthier lives.

Combined with a perception of competing responsibilities, insufficient resources and an unresolvable trilemma, carers appeared to express a similar helplessness. This was expressed through their identification of a lack of motivation among participants with an intellectual disability. However, carers were less likely to be aware of the systemic factors that created barriers between participants and the resources required to live healthier lives. Instead, they were more likely to explain to a lack of success by referring to intrapersonal participant characteristics. These included low motivation, a preference for unhealthy behaviours, or the cognitive limitations described by the intellectual disability diagnosis.

The included studies were remarkably similar, with the synthesis highlighting only one area of difference. This was focused on the health knowledge held by people with an intellectual disability. While some studies inferred a good understanding of health, health behaviours and their associated outcomes, others thought participants' responses lacked depth. The reciprocal synthesis based on the included studies suggests that participants' health knowledge may be fragmented, lacking an underlying coherence that would allow it to be applied flexibly and across contexts. This was noticeable in the information and concerns people with an ID held about their safety during physical activity and meal preparation compared to a lack of concern regarding the consequences of drinking alcohol or smoking tobacco. It may be that the inconsistent understanding of, and approach towards health by carers is reflected in the fragmented health knowledge demonstrated by participants. Participant quotes and primary author interpretations point to unpleasant subjective experiences due, at least in part, to incomplete health relevant information held by participants and their carers. This included confusion, frustration and reduced self-efficacy that in turn affected the intentions and motivation of both groups to pursue health promotion.

Clinical Implications

This synthesis suggests that medium and long-term health benefits appear to be substantially less motivating than short-term experiential and social rewards. This study recommends that efforts to support people with an intellectual disability to live healthier lives are developed in collaboration and at an individual level. For example, rather than concentrating on how levels of physical activity can be increased in isolation, a more successful approach may be to focus on how increasing access to pleasant and personally meaningful activities could increase levels of physical activity as a natural consequence.

A second recommendation is that health promotion efforts should be both accessible and meaningful in relation to the daily lives of people with an intellectual disability. Based on the included studies, efforts to support healthier lives tended to be more accessible when health-related information was paired with choices participants would encounter during their daily routines. Such approaches are more likely to be accessible and serve to make health information concrete and explicit (Salomon et al., 2019). There is also less likely to be an issue with accessing necessary resources that could trigger unpleasant self-judgements. It is recommended that health promotion and disease prevention efforts are presented in this manner rather than through didactic or programmatic approaches.

Carers tend to form the majority of social contacts for people with an intellectual disability, and all people's behaviours are influenced to a greater or lesser extent by their social environment (Lapinski et al., 2014). The high turnover of care staff in formal care settings in which most people with an intellectual disability reside (Leser et al., 2018), combined with the lack of a single definition of a healthy lifestyle or guidance on how to promote it, may create significant inconsistency and uncertainty regarding what health is within these environments. Inconsistency and uncertainty are unpleasant states that may create the conditions for learned helplessness and resulting low self-efficacy and low motivation for both groups in relation to living healthier lives. It is therefore recommended that organisations responsible for the

support of adults with an intellectual disability develop a coherent definition of a healthy lifestyle and guidance for its consistent incorporation into participants daily lives at an individual level. A final recommendation is that this definition and directions for its use are presented to carers and the people with intellectual disabilities they support at the same time.

Research Implications

A strength of the present review is the systematic approach to the development of the research question and search terms employed in the literature search. An additional strength is the development of a synthesis that provides an interpretative window on the perspective of people with an intellectual disability towards living healthier lives. The synthesis offers new insight on the challenging issue of promoting health among this population, including suggestions for how to approach problems such as a perceived lack of motivation. Further, by directing efforts towards redressing inconsistencies and barriers at interpersonal and organisational levels it is thought that healthier behaviours may emerge as a natural consequence of increased opportunities to live personally meaningful and more fulfilling lives.

This study suggests that people with an intellectual disability may benefit more from experiential exposure to health-related information compared to didactic education programmes. Future research could test this assertion by critically evaluating the hypothesis that efforts to support people with an intellectual disability to live healthier lives will be more successful if focused on increasing opportunities to engage in personally meaningful activities that pair healthy options with social and intrinsic rewards.

Though this review focused solely on behaviours related to physical health, health is a broader concept that includes social, emotional, and spiritual well-being (Eriksson & Lindström, 2008). Any approach to a healthier lifestyle will benefit from research that seeks to develop a coherent definition of what such a lifestyle entails. Such a definition would need to account for the unique intersection of intrapersonal,

interpersonal, community and organisational factors that define the contexts in which people with an intellectual disability often live (Pérez-Wilson et al., 2020).

Limitations

The following limitations apply to the present review. Of the 12 included studies, 9 focused on physical activity, either alone or in combination with a healthy diet. Consequently, the findings from this study may be more applicable to physical activity as a component of a healthy lifestyle than they are to diet, smoking cessation, or reduced alcohol consumption.

The present review only considered studies published in English. People with an intellectual disability are estimated to account for approximately 2% of the global population. There may be significantly more literature concerning this topic in other languages that were not included in this study. In addition, the included studies were conducted in solely westernised societies where intellectual disability services are a dominant approach to meeting the needs of this community. In other societies alternative approaches to both supporting people with an intellectual disability and promoting their health may exist. Findings from this review are therefore only applicable to western societies.

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Chapter 2: Empirical Paper

Experiences of the Annual Health Check Process amongst People with an Intellectual Disability

This paper will be adapted for submission to the Journal of Intellectual Disability Research.
(See appendix 3 for Author Guidelines)

Word count (excluding tables, figures and references): 7924

Introduction

Research Aim and Significance

This study aims to explore the lived experience of an Annual Health Check (AHC) from the perspective of people with an intellectual disability. Approximately 1.5 million people currently living in the United Kingdom (UK) have received an intellectual disability diagnosis (Office of National Statistics, 2018). People who receive the diagnosis perform significantly lower than average on cognitive assessments due to atypical neurological development during childhood (Hatton et al., 2017). The diagnosis describes the effect of this development in terms of difficulty with communication, understanding new or complicated information, learning new skills, coping independently, and maintaining a stable routine while managing the demands of daily life (Sheehan et al., 2018).

People who receive an ID diagnosis are 58 times more likely to die before the age of 50, and 4 times more likely to die from a preventable cause compared to the general population (Walmsley, 2011). Unequal access to preventative and timely healthcare has been identified as a contributing factor to these health disparities and early deaths (Edwards et al., 2018). In 2008 NHS England launched the Annual Health Check, an incentivised program to encourage General Practitioners (GPs) to offer regular preventative health screening to their intellectually disabled patients (Panca et al., 2019). Research has since demonstrated the AHC's effectiveness in identifying unmet health needs and undetected, potentially fatal conditions (McConkey et al., 2015); increasing the knowledge held by health professionals and carers about the health needs of intellectually disabled patients (Robertson et al., 2014); and promoting awareness of healthier lifestyles among this group and their carers (Sheehan et al., 2018). Healthier lifestyle behaviours in turn reduce the risk of experiencing mental health difficulties for people with an intellectual disability (Teychenne et al., 2020).

Despite these benefits AHCs reach just over half (57.8% as of April 2020) of the intellectual disability population in England (NHS Digital, 2021). It is still not clear whether people with an intellectual disability actively choose not to attend AHCs, and if so the reasons for that choice. Further research is needed to understand how this group experiences the AHC process that may highlight both personal and inter-personal barriers to inclusion and participation (Chapman et al., 2018).

Review of Existing Literature

Walmsley (2011) interviewed a non-random selection of GPs who had begun providing AHCs. The project also surveyed members of a self-advocacy group on their experiences of their GP surgery and health appointments, including one member's reflective account of a recent AHC. The importance of courtesy, good communication and the attitudes of staff were highlighted. The reflective account noted that the appointment had not differed from a routine appointment, raising questions about its quality and effectiveness. The GPs apparent positive view of their practice, "we treat (patients with an intellectual disability) the same as everyone else", was thought strange by the person with an intellectual disability (Walmsley, 2011, p.164). Their account went on to highlight the need to treat people with this diagnosis differently and fairly because "Being treated the same as everyone else often means that we are excluded" (Walmsley, 2011, p.164).

Chauhan et al. (2012), in a report for the Department of Health, presented combined findings from three studies. In one study semi-structured interviews were completed with 32 people with an intellectual disability and carer dyads to discern the acceptability of AHCs. Overall, people with the diagnosis and their carers described positive views of the AHC but did not always understand the difference between AHCs and standard appointments. Non-engagement was not a common theme, but poor uptake of AHCs was related to difficulty making or attending appointments. These included communication difficulties at the practice, service and individual level. Continuity of the healthcare professional conducting the AHC was consistently

reported as important to both the person with an intellectual disability and their carers.

Tyson et al. (2016) surveyed carers and people with an intellectual disability who had or had not attended an AHC in the past year. Their aim was to discover what led to the reported low uptake, and the level of carer satisfaction regarding those that had been attended. Reasons for not attending included behaviours that challenge, a carers own health, lack of support, travelling distance, and the health of the person with an intellectual disability being perceived as good enough not to need an AHC.

Chapman et al. (2018) asked whether health consultations for people with an ID met expectations. Their aim was to explore the benefits and disadvantages of the AHC. Employing a narrative literature review the authors found that the AHC correlated with improvements in health outcomes. However, attendance was found to be low (approximately 50%) and provision was not countrywide. The importance of patient satisfaction in tackling health inequalities, and the shortcomings of current methods to measure satisfaction were highlighted. Interpretative methods were recommended for future research to capture the perspective of the person with an intellectual disability that may highlight ways to improve their experience of health consultations.

Rationale and Research Question

There are three main limitations of the previous literature. The first is that the majority did not explore in detail the experience of an AHC from the perspective of the person with an intellectual disability. Second, while previous research has described how the attitudes of people with an intellectual disability towards health appointments are strongly influenced by previous experiences, satisfaction measures currently used in primary care are not designed to capture their views (Chapman et al., 2018). Third, each previous study highlighted the importance of the interaction between health professionals, the person with an intellectual disability and their carer. When surveyed GPs often describe their own lack of knowledge in how to interact with and treat people with an intellectual disability (Walmsley, 2011).

None of the previous studies investigated in detail how people with an intellectual disability wished to be treated during AHCs, or the aspects of the process that were unsatisfying.

The result of these limitations is that we currently have little insight regarding the expectations and attitudes people with an intellectual disability hold towards the AHC, or how this affects their choice to attend. This study therefore aims to answer the question “what are the lived experiences of people with an intellectual disability diagnosis who go through the AHC process?”

Methodology

Research Design

Interpretative Phenomenological Analysis (IPA) is a qualitative approach that aims to provide a detailed description of subjective experience and how the experiencer makes sense of a specific event (Smith & Osborn, 2015). It is distinct from other qualitative methods that seek to fit individual experiences within a pre-existing theoretical understanding, or develop new theories based on participant accounts (Smith & Osborn, 2015). This difference results from the methods phenomenological, hermeneutic and ideographic basis. IPA is phenomenological, focusing on unique experiences; hermeneutic in attending to how participants make sense of and incorporate experience into existing systems of meaning; and ideographic through the depth of analysis and exploration of this integration to produce a description of how the experience is understood by the participant (Smith et al., 2009).

IPA was considered the best method to answer the study's research question for the following reasons. The question focuses on the experience of the AHC process for people with an intellectual disability. The necessity and challenge of including people with an intellectual disability in research about their lives is well recognised (Carey & Griffiths, 2017). A common criticism of qualitative research with this group is the use of proxy accounts in combination with or instead of the person with an intellectual disability (Tomlinson & Hewitt, 2018). Inclusive research seeks to engage people with an intellectual disability so that they are not just the subject. The aim is instead to address issues that are important to people with an intellectual disability, in ways that improve their lives and increases their voice within the literature (Hollomotz, 2018). IPA is inherently inclusive, focusing on and giving priority to the experience of the experiencer in ways that cannot be provided by proxies (Tomlinson & Hewitt, 2018). IPA further enhances its inclusivity by asking participants to critique the interpretative results of a study in terms of how well it represents their experience (Beail & Williams, 2014).

Conducting qualitative research with the intellectual disability population can present challenges related to the impairments the diagnosis describes. They include the heterogeneity of the population, difficulties communicating their lived experience, and an increased risk of acquiescence or responses motivated by social desirability (Beail & Williams, 2014; Hollomotz, 2018). IPA is less concerned with the homogeneity of the sample and more with the homogeneity of the phenomenon of interest, and the ability of participants to describe their experience of it (Beail & Williams, 2014). IPA places responsibility for effective communication onto the researcher. It is their job to create the conditions and be guided by participants as they freely describe their experiences (Smith et al., 2009). This helps to reduce the likelihood that participants will feel the need to give 'the right answer' (Hollomotz, 2018).

A further consideration is that those who choose to conduct research with people with an intellectual disability tend to have familiarity with and pre-existing views of their experiences (Corby et al, 2015). IPA accounts for this through awareness of the double hermeneutic, that the researcher is making sense of the sense made by participants (Smith et al., 2009). The process by which the researcher makes sense of participants descriptions, in addition to the researcher's context and pre-existing biases, are made explicit in the description of the study's methods and findings (Tomlinson & Hewitt, 2018). This aids the reader in distinguishing the voices of participants from the voice of the researcher.

Participants

Sampling

The study used a non-probability purposive sampling design to recruit participants based on the inclusion and exclusion criteria detailed in table 2.1. UK based private and charitable organisations offering support to people with an ID were approached to promote the study and recruit participants.

Inclusion and Exclusion Criteria

Table 2.1 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Age	18 years and older	Younger than 18 years old
ID Diagnosis	Eligibility for and experience of attending Annual Health Checks for people with an intellectual disability diagnosis	Persons without an intellectual disability diagnosis Persons who have not attended an Annual Health Check
Mode of participation	Able to communicate using sentences or short phrases	Unable to communicate verbally
Medium of participation	Access to and ability to correspond (with or without support) using letters, e-mail or video or telephone calls	Without access to or ability to engage through written or digital mediums of communication

Adults who had received an intellectual disability diagnosis, had experience of receiving an AHC, were able to communicate verbally and had access to video or telephone communication were included in the study. This last inclusion criteria was needed in response to the COVID-19 pandemic to reduce the risk to participants and researcher presented by face-to-face interviews. It is acknowledged that this may have presented additional barriers to participation and is discussed in the limitations section of this study.

Sample Size and Participant Characteristics

Novice IPA researchers are advised to recruit between 6-10 participants (Smith et al., 2009). IPA also requires the researcher and participants to explore their experience to a sufficient level of psychological depth (Smith et al., 1999). For this reason and based on recommendations for the use of IPA with this population, the study aimed to recruit a minimum of 10 participants (Beail & Williams, 2014).

In total 12 participants were recruited to the study. Table 2.2 outlines the pseudonyms given to each participant (and carer if present) for the purpose of anonymity. Additional information (where participants chose to give such detail) on age, ethnicity, additional developmental and health diagnoses, living arrangements, and level of support received is included in table 2.2. This information is provided to support the reader to situate the sample. The level of daily support a person with an intellectual disability receives can be used to infer their functional independence skills, with greater support tending to be required where fewer skills are possessed (King et al., 2017). This was considered an important characteristic as the level of functional independence (specifically skills that facilitate the use of communication technology, coordinating transport and general self-organisation) would likely affect the type and quality of experiences participants were exposed to during the AHC process. In addition to an intellectual disability, the presence of a developmental or physical condition can exacerbate difficulties related to cognition and communication, as well as add further challenges in terms of information processing and interacting with others (Wullink et al., 2009).

Table 2.2 Participant pseudonym and demographic information

Pseudonym	Age	Gender	Ethnicity	Location	Living Arrangements	Additional Diagnoses and Support Arrangements
Scott	29	Male	White British	North England	Lives alone in own home	Scott had also received an ASD diagnosis. He received set hours of support 3 times a week. Scott's interview was arranged at his request to coincide with his support hours and one of his support workers was present during the interview.
Carla	33	Female	White British	Midlands England	Lives alone in own home	Carla had also received an ASD diagnosis. She received regular support from family. Carla was supported during the interview by her Mother. This included help to communicate, recall details, and use the technology required to hold a video call.
Robert	52	Male	White British	Midlands England	Lives in a supported living setting	Robert described having hearing difficulties in both ears. He was offered regular support each day. Robert was supported during the interview by a member of his support team, Mary, to communicate, recall details, and use the technology required to hold a video call.
Rose	63	Female	White British	Midlands England	Lives alone in own home	Rose described muscle weakness in her arm and leg down one side of her body due to polio. She received no regular support. Rose requested to have Denise, a volunteer facilitator of a self-advocacy group, present during her interview in order to access and use the technology required to hold a video call.
Louise	34	Female	White British	Midlands England	Lives alone in own home	Louise had also received an ASD diagnosis. She received set hours of support during the week. Louise requested to have Denise, a volunteer facilitator of a self-advocacy group, present during her interview in order to access and use the technology required to hold a video call.

Mihran	47	Male	British Asian	Midlands England	Lives alone in own home	Mihran received regular support from family. He was supported to engage with his interview by Jean, a self-advocacy group facilitator. This support included meeting before the interview, reviewing the interview schedule, and thinking about how he might answer these questions.
Ivaan	30	Male	British Asian	Midlands England	Lives alone in own home	Ivaan had also received cerebral palsy and epilepsy diagnoses. He received regular support from family. Ivaan was supported to engage with his interview by Jean, a self-advocacy group facilitator. This support included meeting before the interview, reviewing the interview schedule, and thinking about how he might answer these questions.
Jude	47	Female	White British	South Wales	Lives alone in own home	Jude had no regular support arrangements and engaged independently with her interview.
Anna	36	Female	White British	Midlands England	Lives in a supported living setting	Anna had received ASD and CFS diagnoses. Anna can request support from accommodation staff and contracts a second care company to provide set hours of support during the week. Anna was joined by Marta, a carer employed by the second company.
Helen	47	Female	White British	Midlands England	Lives in a residential care setting	Helen received regular support each day. She was supported during the interview by Vicky, her keyworker, to communicate, recall details, and use the technology required to hold a video call.
David	64	Male	White British	North England	Lives alone in own home	David had received a diagnosis of epilepsy and received regular support from family. He engaged independently with his interview.
Teri	49	Female	White British	South England	Lives in a residential care setting	Teri had received a diagnosis of cerebral palsy. She had access to support throughout the day. Teri engaged independently with her interview.

Materials

An invitation to participate letter (Appendix 2.1), participant information sheet (PIS, Appendix 2.2) and informed consent form (Appendix 2.3) were developed prior to recruitment and in consultation with an Expert Reference Group (ERG). The group was comprised of people with an intellectual disability who were experienced in advising an NHS Trust on the accessibility of their services and published information. Members of this group were not recruited to the study. The PIS was developed to provide potential participants with accessible information about the study. Three versions of the PIS were developed, one using accessible text with corresponding pictures (Appendix 2.2.1); one using only the accessible text (Appendix 2.2.2); and a third using the standard language of the PIS template provided by Coventry University Ethics (Appendix 2.2.3). The consent form was designed in reference to the PIS to ensure that potential participants understood what taking part would involve. Study materials were also reviewed for accessibility by a Speech and Language Therapist (SaLT) with experience assessing the communication skills of people with an intellectual disability and ensuring information was accessible to them. The completed materials were reviewed by a second ERG who were not participants in the study. They were satisfied with the presentation and accessibility of the materials.

A semi-structured interview guide was developed (Appendix 2.4) in collaboration with the research supervision team. The guide was structured using a view of the AHC as a process, with stages that people with an intellectual disability must go through. These were understood to be 1) being invited to and arranging their AHC, 2) preparation for and arrival at their GP surgery on the day of the appointment, 3) the AHC appointment, and 4) related events that happened after the AHC. The design of the interview guide, and the data collection and analysis stages of the study were also informed by recommendations for IPA research with the intellectual disability population made by Rose et al. (2019). While IPA interview guides tend to be short, using a few open ended and non-leading questions, people with an intellectual disability may struggle to recount their experience in the required depth without

additional structure (Hollomotz, 2018). Additional prompts were included to ensure a fuller exploration of participant experiences while taking care not to lead responses.

A debrief letter was also developed (Appendix 2.5) using the same wording and images from the relevant sections of the PIS. It included thanking participants for their contributions and repeated the information they needed to know should they wish to contact the researcher or withdraw from the study. To support recruitment through social media and digital platforms a poster and video were also developed based on the invitation letter.

The readability of all study materials was assessed using Flesch Reading Ease (Flesch, 1948) and Flesch-Kincaid grade level scores (Thomas et al., 1975). Both are widely used measures of a document's accessibility, and Flesch Reading Ease is considered a good proxy for ease of understanding when questions are read aloud (Thompson et al., 2016) (see Appendix 2.6 for accessibility scores).

Recruitment Procedure

Though several avenues were explored to recruit participants (including the use of social media and advertising on the websites of agencies who provide support to and campaign on behalf of people with an intellectual disability) successful recruitment only occurred through self-advocacy organisations.

This study was conducted during the COVID-19 pandemic. Following the first UK national lockdown in response to the pandemic and the suspension of in person services, many self-advocacy groups moved regular meetings and social events online. Co-ordinators for online groups were contacted and informed about the study. They were provided with copies of the accessible invitation letter and participant information document. If they felt it appropriate, they were asked to share this information with group members. If the group was interested the researcher was invited to an online meeting to talk about the research.

Via these groups potential participants were shown a brief accessible video describing the study and were able to ask the researcher questions. Those who were interested in taking part were asked to let their group organiser know. The group organiser then shared their contact details with the researcher. The researcher contacted potential participants (via post, e-mail or telephone depending on their preference) and provided them with a copy of the accessible participant information sheet and encouraged them to discuss the study with a trusted other. Potential participants were given time outside of contact with the researcher to read and discuss the participant information sheet and consent form. Potential participants who wanted to take part completed the consent form and were provided with a further opportunity to ask questions. Between October 2020 and January 2021, the researcher met with six self-advocacy groups, presenting the study to a total of 66 attendees. Of these, 35 people with an intellectual disability expressed initial interest, with 12 returning an informed consent form and completing an interview.

Interview Procedure

A suitable time and date were arranged with each participant. Before the interview began participants were offered another opportunity to review the PIS, to ask questions and were reminded of their right to withdraw. Interviews were conducted using the interview guide and were video and audio recorded using Microsoft Teams. As each stage of the AHC process was discussed the researcher summarised and checked their understanding with the participant. Where necessary, clarification was sought to ensure that the researchers understanding accurately matched the participants' experience. Once the interview was completed the participant was given time to ask questions, provided with a copy of the debrief letter and thanked for their participation. Participants were also asked if they would be happy to be contacted for comment on the results of the study. Their preference was noted on the consent form.

Data Analysis

Each interview was transcribed verbatim, with the names of people and places changed to preserve participant anonymity. Following transcription, the recordings were deleted. The transcripts were then analysed in the manner outlined by Smith et.al. (2009). Individual transcripts were read repeatedly to develop a line-by-line familiarity of what happened and how. Sections of text that indicated they referred to something important to the participant were highlighted and an initial interpretation was made. Where participants were supported by a carer caution was taken to base interpretations only on the participants own words. These interpretations provided the basis for themes. These steps were repeated for each participant and commonalities across transcripts provided the basis for shared themes and superordinate groupings.

Coding, emerging themes and final themes were discussed with the research supervisor. In line with Rose et al.'s (2019) recommendations, each theme was supported by quotes from at least 6 of the 12 participants. A full list of supporting quotes for each theme can be found in Appendix 2.7. To confirm that these findings faithfully represented the experiences of participants an accessible summary of the results was shared with those who gave consent for the researcher to contact them for this purpose (Appendix 2.8).

Ethics

Ethical approval for this study was received from Coventry University Ethics (Appendix 2.9). It was conducted in line with the British Psychological Society Codes of Ethics (2018) and Research Ethics (2014). Additional consideration was given to the design of study materials to ensure they were accessible, and participants had access to the information necessary to make an informed decision regarding participation. In keeping with the principles of inclusive research both ERG groups were asked to comment on the focus and nature of the research question. All

members of both groups agreed that AHCs were important to them and that the current study aimed to answer questions that could lead to improvements.

Researcher's Position

Though the goal of qualitative research is to faithfully represent the voices of participants, it is the researcher who asks the questions, analyses their contributions, and presents the results (Nind, 2008). The interpretative double hermeneutic of IPA requires bringing awareness to the identity of the researcher and their pre-understandings so that they do not unknowingly bias study results (Smith et al., 2009).

Bracketing is a process by which the researcher identifies and describes their pre-existing assumptions of the phenomenon of interest (Rose et al., 2019). Before interviewing participants, the researcher completed a bracketing interview. The interview was supported by a clinical supervisor with experience working with people with an intellectual disability. The researcher had also maintained a reflective log since the initial design stages of the study. Excerpts from the log were used as a guide for the bracketing interview, beginning with a full description of the researchers experience of the AHCs.

Previously, as an Assistant Psychologist, the researcher had supported GPs while they provided AHCs to adults with an intellectual disability. In developing the study, the researcher had also reviewed existing literature regarding AHCs and more general experiences with healthcare, and the associated views of people with an intellectual disability and their carers. Combined, these had left the researcher with two main assumptions. The first was that primary care professionals offering AHCs were more likely to be poor communication partners for people with an intellectual disability. Second, these poor communication experiences would be a significant factor in any dissatisfaction expressed by participants.

Results

Table 2.3 – Superordinate and subordinate themes

Superordinate Themes	Subordinate Themes
Theme 1: <i>“It’s good for me”</i>	<i>“It helps you knowing you’ve been kept healthy”</i> <i>“I have someone with me to help me”</i>
Theme 2: <i>“That doctor does his job, but they treat you as a person”</i>	<i>“The people what do it, they care”</i> <i>“You want the doctor to actually know the person”</i>
Theme 3: <i>“I think doctors should be a bit more understanding with disabilities”</i>	<i>“Haven’t you looked at my records?”</i> <i>“You’ve got to have something to back you up, to help you”</i>

Analysis of the experiences ‘voiced’ by 12 people with an intellectual disability describing their Annual Health Check (AHC) resulted in three superordinate themes and six subordinate themes (see Table 2.3). Each superordinate theme was supported by quotes from all 12 participants. Table 2.4 (below) illustrates the variation in the representation of each participant’s account within the developed themes and sub-themes.

Table 2.4: Superordinate and subordinate themes cross-referenced to participants

Participant	Theme 1		Theme 2		Theme 3	
	Sub-theme 1	Sub-theme 2	Sub-theme 1	Sub-theme 1	Sub-theme 1	Sub-theme 2
Scott		•		•	•	•
Carla	•	•	•	•	•	•
Robert	•	•	•			
Rose	•	•	•	•	•	•
Louise	•	•		•		
Mihran	•	•	•		•	•
Ivaan	•	•		•	•	•
Jude	•	•	•	•		•
Anna	•	•	•	•	•	
Helen	•	•	•			
David	•	•	•			•
Teri	•	•	•		•	•

To support a critical evaluation of these results an excerpt from one participant's transcript detailing how the analysis progressed through the descriptive, linguistic and conceptual stages is provided in Appendix 2.10. An excerpt of how theme 2 was developed from individual participant quotes is provided in Appendix 2.11. Additional supporting quotes for each theme are included in Appendix 2.7.

Theme 1: *"It's good for me"*

All 12 participants described how they viewed the AHC as beneficial and supportive of their desire to *"keep healthy"* (Jude, line 103). Theme 1 summarises how participants both understood that the AHC was meant to help them stay healthy and attended with personal health-related goals in mind. As such, participants held expectations that influenced their experience. The first sub-theme illustrates how they were aware of their greater susceptibility to poorer physical health, and how the meaning of being *"kept healthy"* (David, line 181) could differ. The second sub-theme illustrates how participants also identified a need for extra support to access services meant to help them stay healthy.

"It helps you knowing you've been kept healthy"

Participants voiced their awareness of, and at times concern about, the health disparities people with an intellectual disability face. As Jude put it: *"we need it done (the AHC) because people with a learning disability die young...and I don't wanna die just yet"* (line 99-100). When describing what he thought was good about the AHC Ivaan replied *"because otherwise...I mean you wouldn't know what kind of health problems you have"* (line 243-244). Responses like these were interpreted as an indication that participants were aware of their greater susceptibility to ill health compared to the general population, and that they may not recognise the signs of ill health without the help that the AHC was meant to provide.

Some participants also expressed anxiety that due to the COVID-19 pandemic, the normal physical checks had not been performed during their most recent AHC:

"I suppose because they (health professionals) rang me over the phone and then...they were obviously asking me the normal questions...but then they, they couldn't do the routine blood test and anything else that they should have been doing....it might've been better to have one even though they said I didn't need one, just in case" (Louise, line 45-52)

Louise's use of the word "*should*" was echoed by other participants. This suggested that alongside the AHC being viewed as a source of help to stay healthy, participants had also developed ideas about how that help should look and feel. When asked what kept her going each year Louise explained *"I suppose it's, I keep going because it's a chance if they find anything, if there's anything going on that they (the health professionals) can't see, then they can find it can't they"* (line 776-777).

The AHCs were also viewed as an important opportunity for participants and their doctors to monitor existing health conditions. For example, Jude explained *"I'm, sort of borderline diabetic, not diabetic just yet, I'm getting there slowly, so like, I've gotta be careful"* (line 87-88), adding that because of this her doctors *"definitely keep an eye on me"* (line 97). These and other participants descriptions suggest that for some the physical examinations during the AHC could be more important than the questions they are asked. For these participants it seemed that they attended their AHC with the aim of being reassured that they had not developed a new health condition, or that an existing condition had not worsened.

For other participants the AHC seemed to be less about avoiding worsening health and more an opportunity to receive support to stay healthy:

"Oh I think they're good!...I think it helps people. It helps you knowing you have been kept fit, healthy, and it helps them (primary care staff) to know what they've done is right, and they're trying to keep you healthy...even if you don't go all the time but you go for that, it helps." (David, line 179-183)

Based on these experiences it appeared that people with an intellectual disability are aware of their need for an AHC and expect their physical health to be checked regularly. What's more, they appear to have expectations about how the AHCs should be conducted in order for them to be helpful. What appears to differ are the functions those expectations serve. Some participants were motivated by a desire to be reassured that they were not ill, or that if they were it would be detected early. For others, it was about ensuring that their existing health conditions were well monitored and prevented from worsening. In both cases the physical checks appeared to be an important marker of their AHCs quality. For the remaining participants the AHCs supported their efforts to maintain good physical health.

“I have someone with me to help me”

Each participant described practical challenges they encountered when accessing health services, as well as receiving help from a carer or family member to overcome them. When asked what made the difference between a good and a bad AHC several participants talked about how their appointment was made:

Mihran: “...sometimes they (primary care staff) make appointments on the telephone rather than send a letter...on the telephone is more difficult because we have to check the calendars and things like that.”

Interviewer: “So for you being invited by letter is easier?”

Mihran: “Well, rather than telephone, yes....I think once upon a time it was, it was letter. But, it has increasingly been on the telephone actually.”

Interviewer: “And they ask to speak to you?”

Mihran: “Um, most of the time, but sometimes my Mum gets it.”

Interviewer: “So they call, you said that's not as easy for you?”

Mihran: “Well, um, ooh, alright, I have to admit something, I don't have too much telephone skill so my Mum does it for me most of the time.”

Interviewer: “If it's by phone, how do you feel about that?”

Mihran: “Well I don't know, it might be better by letter actually.” (Mihran, line 285-303)

Mihran's preference for a letter was shared by other participants, and may suggest a desire to be able to manage this stage of the AHC process more independently:

"...it's more better when I've got somebody with me than on my own because it's a bit difficult sometimes....I like having help if I can. But sometimes I want to do some things on my own, if I can. And then sometimes, if I can't, I want somebody." (Rose, line 383-388)

Each participant's descriptions suggested that people with an intellectual disability encounter difficulty from the outset of the AHC process, and that such difficulty can trigger feelings of stress, reduced independence, and embarrassment:

"Well, if you're on your own and you're doing it, if you've got stuff like that (appointments) you could forget. And that means that, that's wasted, then when you realise you know you're gonna feel a right fool you might say. But if you've got back up you've got someone to give you a little nudge, you know, to say something, and it could help you." (David, line 329-332)

Managing the demands of communication was another area where problems could arise:

Interviewer: "...what's that like Robert to have to have someone there to help you to talk with the doctor and to help the doctor talk to you?"

Robert: "Uh, if I say something then me ask the staff to help me to talk about it, to the doctor, and the staff tell them....In case...say hard words...For me (points to self) hard words."

Carer: "When Robert is saying hard words he means he finds it very hard to get the right words to express himself."

Robert: "Yes." (Robert, line 115-134)

In addition to these practical challenges simply being in the GP surgery, with its connections to illness and injury, could be a source of difficulty:

Interviewer: "And having someone go with you, does that make it easier or harder?"

Scott: "Easier."

Interviewer: "How does it make it easier?"

Scott: "Um, just with someone I trust. It's emotional support."

Interviewer: "What kind of emotions show up for you?"

Scott: "Anxiety mostly. I can get very anxious very quickly, and then I start panicking, like crazy." (Scott, line 285-291)

Participants appeared to be very aware of potential barriers at each stage of the AHC process, the nature of the challenges presented, and the need for additional support to overcome them. Participants' descriptions also suggested that they would have preferred greater independence in how they engaged with the AHC process. Far from reducing barriers to accessing healthcare, the way people with an intellectual disability were being asked to participate in the AHC seemed to make it harder.

Theme 2: *"That doctor does his job, but they treat you as a person"*

All 12 participants described the central importance of their interactions with primary care staff in determining the quality of their AHC. Theme 2 summarises how the experience of feeling "*valued*" (Anna, line 66) and cared for by primary care staff resulted in participants also feeling satisfied with their AHC experience. The first sub-theme illustrates how what appeared to matter most was being treated respectfully as an individual. The second sub-theme communicates how knowing and being known by primary care staff gave participants confidence that they would be treated respectfully and that their AHC would be done properly.

“The people what do it, they care”

Being able to “*have a bit of fun*” (David, line 61) with primary care staff seemed to be important to some participants:

“Well, if you go in and you sit there and you get tense, by the time you’ve gone in you’re tense, the person what’s doing it’s tense, and they’re not learning, not getting anything, in a way, because the both of you are tense. But if you go in there and have a bit of fun, or have a joke, you know what I mean, a laugh, it puts them at ease, you put yourself at ease and you just get on with what they want to do without thinking of it.” (David, line 59-63)

Many participants identified helpful ways primary care staff had behaved towards them. Helen talked about the nurses who took her blood sample, “*they have a chat with me first before they start to do it...they’re good to chat with, it’s just reassuring*” (line 405-406). Teri shared an example where primary care staff had visited her at home:

“...in my other house the doctor, the nurse came round to my other house, and knocked on my door, says “it’s due, your health check. We’re coming here to do it.” And that made me feel relieved, I didn’t have to sit in the surgery.” (Teri, line 654-659)

Robert had noticed a difference between two doctors and how they accommodated his hearing impairment and his efforts to compensate by attending to facial expressions:

Interviewer: “What is it about the lady doctor that you would rather have?”

Robert: “Nice to listen to them...And face to face.”

Interviewer: “And the man doctor, does he not always...” (interrupted)

Robert: “Sometimes...he’s...writing and talking.”

Interviewer: “Which means that you can’t see his face?”

Robert: "No, not really. Only the lady do it, and lady finish talking and then write it down." (Robert, line 703-715)

When asked what it was like to talk to those delivering her AHC Carla described how she felt the appointment *"should"* be done:

"...she fit the questions around me. Which is what you should do. Because I know you've got a checklist, but you need...to think "ok, that will apply to her". And she does, she asked me questions...that wasn't on the checklist which was good...She fit the questions around me." (Carla, line 894-910)

While participants' examples of being respected as an individual varied, they all involved some form of inter-personal connection with primary care staff. For some, like David, being treated *"as a person"* (David, line 558) meant receiving and engaging with their attempts to *"have a bit of fun"* (David, line 61). This in turn helped him to feel more at ease, and he believed it did the same for those delivering his AHC. For others, like Teri and Robert, it seemed to be about their needs being noticed and accommodated in a way that could reduce the challenges around the AHC. And for participants like Carla it meant conducting the AHC in a way that made it feel *"relevant"* (Carla, line 280) to their health needs. What seemed to be shared across participants' examples was a recognition of them as people with individual human needs, and a willingness from primary care staff to acknowledge and meet those needs.

"You want the doctor to actually know the person"

Many examples of how participants were made to feel respected also seemed to involve familiar and preferred primary care staff:

"...I know her (the doctor), I've had her before...and she's quite nice with me. If I'm on my own, if I take my coat off she'll help me, and stuff, she's really

good. Some of the other doctors they don't help me at all like she does."

(Rose, line 154-156)

When asked what made an AHC a good experience participants often mentioned their familiarity with the primary care staff involved:

Ivaan: "...you see the same nurse all the time, and she, the nurse understands all the background information and the health check...that has been back in the past and that, it's unbelievable."

Interviewer: "And how do you feel that it's the same nurse and the nurse knows your history?"

Ivaan: "Yeah, I feel great because, she knows me so well..." (Ivaan, line 173-178)

Knowing the health professional may also have given some participants the confidence to make requests so that their health checks were more specific to their individual needs:

"Well, with the nurse I tell her...look in my ears...I like that done. In the past...they hadn't done it. That's why, one year...I couldn't hear out of both...It was terrible. I didn't like it and I don't want it to get as bad as that."

(Rose, line 748-768)

Familiarity also seemed to help reduce some of the difficulties participants encountered. Anna explained that during the first national lockdown she had been unable to arrange to see her own doctor for her AHC:

"I only managed to get to have the annual check with my own doctor because I happened to have an appointment with the nurse and I told her what's been going on and she said "Don't worry, I'll sort it". And I managed to have a video meeting with my own GP, without any problems." (Anna, line 138-140)

It seems evident from participants' comments that their experiences of the AHC would be more positive if they were carried out by doctors and nurses that they already know. Familiarity seemed to provide reassurance and a sense of confidence that the AHC would be a worthwhile experience. This makes sense given what was learned in the previous sub-theme that developing a sense of trust in practitioners is an important part of the health check process for people with an intellectual disability.

Theme 3: *"I think doctors should be a bit more understanding with disabilities"*

Here, 9 participants described how interactions characterised by a lack of understanding of diagnoses and related needs could contribute to an unsatisfactory AHC experience. Theme 3 explores participants' annoyance, frustration, and dissatisfaction when the actions of primary care staff suggested they were unaware of the need for, or unwilling to make, reasonable adjustments. The first sub-theme summarises the frustration, annoyance, and sometimes disbelief experienced by participants when such a lack of understanding occurred. The second sub-theme articulates how, in addition to the need for help to access health services, people with an intellectual disability also felt the need for support to ensure that they and their goals were treated with respect by primary care staff.

"Haven't they looked at my records?"

While familiarity seemed to provide reassurance, a lack of consistency in who participants saw seemed to be connected in their mind with a lack of knowledge regarding their health history:

Ivaan: "...in every single health check it's a different doctor...it's strange for me (laughs) it's really strange for me....because...it's the same nurse but different doctors...."

Interviewer: "And when it's strange are there certain feelings that come up for you?"

Ivaan: "Yeah. By looking at the doctor, I mean (sharp exhale) looking at the information on the computer, getting the background, uh, about yourself."

Interviewer: So are you describing that when you go in and see this new doctor they're looking at the screen and they're trying to find out your history while you're there?

Ivaan: "Yeah, (nodding) That's all they do. That's all they do. But they do...like I said, ask questions about you around health which is so much positive. And I ask questions and answers anyway. But...you know, my mother and me just sit there and...wait until the doctor's finished." (Ivaan, line 194-210)

Experiencing a lack of respect from primary care staff was often voiced by participants in terms of poor awareness of their individual health needs and that the AHC was not being performed properly:

Carla: "I showed it (a period tracking app on my phone) to the lady Doctor...she was interested, but the man Doctor wasn't."

Interviewer: "So you tried to show it to him?"

Carla: "Yeah. I told him that I had this new app, that I record everything on. But he just didn't care....So I could've had something wrong with my vagina and he wouldn't care."

Interviewer: "Is that how it came across? Like he didn't care?"

Carla: "Yeah."

Interviewer: "And what was that like for you?"

Carla: "Annoyed. Because I could have had a problem down there and he wouldn't have given two flying toss" (Carla, line 937-950)

It is rare for people with an intellectual disability to describe their experiences using words like exclusion or discrimination. Instead, they tend to use words and terms such as 'unfair', 'not right', or 'it shouldn't be like that' (Llewellyn et al., 2015).

Participants mentioned different strategies, such as the Health Action Plan, that had been developed to support primary care staff to make reasonable adjustments for

their patients with an intellectual disability. Some participants felt such strategies were ignored by primary care staff:

"I've got...an annual check...folder to write in when I go to appointments as well... because I have no help to take me to doctors or dentist or anything, and I don't take it with me because they (primary care staff) won't write in it and they should!" (Rose, line 229-232)

Most participants gave examples of primary care staff behaviour that seemed to demonstrate a lack of understanding regarding their diagnoses and associated needs. Some expressed surprise at this lack of awareness given how much information they had access to:

Rose: "Well, they've got on their records, they've got it down that we've got problems, what we've got and stuff. Well, one doctor I went to I said "Oh, haven't you looked at my records?" and he said "Oh no, I like people to talk to me".

Interviewer: "What do you think of that?"

Rose: "I thought, (shakes head) not good enough I thought."

Interviewer: "Not good enough because they have all this information about you....And it tells them what you find hard and what things they can do that make things easier. But sometimes they don't read it?"

Rose: "No, you just have to keep telling them!"

Interviewer: "What's that like for you?"

Rose: "I thought "Oh, I've got to do this again. Oh no, not again!" (She sighs) It's just annoying!" (Rose, line 286-301)

Participants in this study had also encountered difficulty due to a lack of awareness concerning their visual or hearing impairments. For example Robert used hearing aids in both ears and described the need to speak *"face to face"* (line 610) to health professionals to be able to communicate with them. During the first national lockdown Robert had an experience where this need was not met. Despite

explaining that for him *“it’s better on video call”* (line 467) his AHC was conducted via phone call. For Robert this was *“not good enough”* (line 427).

Other participants described how the actions of some primary care staff felt like attempts to dictate how they should live their lives:

Teri: “I try to eat sensibly you know. I keep an eye, on different bits, you know.”

Interviewer: “Does that come up in your health check?”

Teri: “Well they offer me the dietician. And I say no because the last time I had a dietician it was very uncomfortable. She made me feel very uncomfortable in the room....I’d be in the room and she would dictate to me what I’ve got to do. And I would say to her “Look I’m not here for you to dictate to, you can advise me on what to do”. I found her very, very patronizing.”

(Teri, line 143-152)

Most participants expressed how a lack of familiarity detracted from the perceived quality of their AHC and the confidence they derived from it. Based on these and similar quotes participants seemed to be surprised and frustrated by how unaware or unwilling to make reasonable adjustments primary care staff could be. This left participants feeling ignored, unimportant, and at times discriminated against. In some cases, participants’ perception of primary care staff’s disrespect seemed to extend beyond their need for reasonable adjustments, broaching on a lack of respect for their individual human right to choose. When participants had these types of experiences, they left feeling dissatisfied, concerned that they had not received the right treatment and unable to achieve their health goals as a result.

“You’ve got to have something to back you up, to help you”

In response to these types of experiences it was common for participants to attend with a *“back up plan”* (Ivaan, line 730) facilitated by a carer or a family member. For each participant who described needing and benefiting from such ‘back up’, it

ultimately seemed to be about improving the accessibility of their AHC appointment. Importantly, this was about reducing both the cognitive and emotional demands of the process:

Rose: "So it's just in case if I need some back up or anything, yeah."

Interviewer: "So when you say, if you need some back up, what might you need back up on?"

Rose: "Well, like, if, something went wrong, or, if I wasn't happy, or if I wanted help..." (Rose, line 826-829)

However, having 'back up' did not guarantee a satisfying experience. At times it could result in the person with an intellectual disability feeling even more excluded and disempowered:

Carla: "Uh, it's like, he doesn't know that I'm there. I look at my Mum because I don't know what to say. That's when I look at my Mum so she can help me with questions."

Interviewer: "So if we were doing this interview, and if I was asking your Mum all the questions, what would that be like for you?"

Carla: "Really annoying." (Carla, line 527-531)

Difficulty could arise where the source of 'back up' had their own goals that may or may not include those of the participant. For example, Mihran mentioned how his mother *"actually gets more excited about my health check than I do"* (line 702). It seemed, based on his descriptions, that he sometimes felt forgotten during his AHC:

"Sometimes...the doctor and nurse talk to my mother...rather than me.... And my mother is so chatty then that it can go on for a few minutes, and sometimes it's really annoying (laughing)....And then sometimes they say "Oh", yes, yes, we're talking about you! The doctor will say" (Mihran, line 61-70).

When asked what he thought about this he replied: *"Sometimes I say, "here we go again", other times I go "oh, no, I just, I just listen to them chatting because I can't do anything"* (line 97-98). Other participants seemed to hold in mind a similar risk that having 'back up' could increase the chances of feeling overlooked or ignored solely on the basis of their intellectual disability diagnosis:

"I say to them "Please don't talk to my support worker. I'm here, I'm a human being. Only talk to my support worker when I need it... sometimes that's the way some doctors think "Oh she's got a disability she might not understand"...that's the impression that I get." (Teri, line 125-132)

When this happened participants described feeling irrelevant: *"It makes me feel frustrated ...It makes me feel like "What's the point in me being there?"* (Anna, line 78-81).

In relation to 'back up' participants voiced both how they felt about relationships with primary care staff that did not support their goals for their AHC, and how they enlisted the support of others to compensate. In many ways 'back up' seemed to be about increasing accessibility and regaining some control over a process that would otherwise have excluded some participants due to a lack of reasonable adjustments at each stage. This was not guaranteed however, and sometimes the presence of that 'back up' invited primary care staff to direct their questions to someone other than the person with an intellectual disability. Far from supporting their goals, occasions such as this left participants feeling unseen, unimportant and powerless.

Discussion

This study interviewed 12 adults with an intellectual disability who had received an Annual Health Check (AHC). Three superordinate interpretative themes were developed to offer a perspective on their lived experience of the process.

Theme 1 presents the interpretation that participants went to their Annual Health Check with their health in mind, alongside an awareness of the difficulties they face in accessing services. Attending the health check meant different things to different participants. For some it was an opportunity to be reassured they were not ill, and if they were it was a chance to catch and treat problems early. For these participants there appeared to be a presumption that ill health would occur, and without the checks it may not be detected before it became serious. This was particularly apparent for participants who were dissatisfied because their appointment this year, in response to the COVID-19 pandemic, had not included all the normal physical checks. For others, it was an opportunity to receive support and advice that would help them stay healthy.

Themes 2 and 3 suggest an interpretation of how participants made sense of primary care staffs' behaviours, whether they felt valued or unimportant as a result, and how it informed their approach to their health check appointment. When participants felt they were treated like a person, and that primary care staff were known to them, they were also more confident that they would receive the right treatment. In turn, this left them feeling reassured about their health. Conversely, when participants felt ignored, unimportant, or that primary care staff didn't care about them, they were less likely to feel that their health check had been thorough. When this occurred, participants left their appointments feeling uncertain about their health and frustrated by how they had been treated.

Current Findings and Previous Research

This study adds to the previous literature by demonstrating how people with an intellectual disability can have different personal reasons for attending Annual Health Checks. It is consistent with previous research detailing how perceptions of past AHCs, and primary care more generally, influenced their expectations of future appointments (Chapman, 2014). This study further demonstrates how participants decided whether or not the AHC was a satisfying experience in relation to how well they were able to achieve their goals for attending.

As with previous research, participant satisfaction was derived from the experience of being at the centre of their health appointment (Mastebroek et al., 2016). In practical terms this meant seeing a health professional who spoke directly to them (Ziviani et al., 2004), used accessible language (Hanlon et al., 2018), did not rush (Perry et al., 2014), explained things in ways that were understood (Flynn et al., 2016), confirmed this understanding, and sought consent to include carers, and only when the patient encountered difficulty (Wullink et al., 2009). Participants in the current study often described the experience of these behaviours as being *“treated like a person”*. The interpretation offered in theme 2 suggests that participants connected these behaviours to the experience of inclusion. In turn, an inclusive experience was more likely to be one in which they felt heard, that their personal health had been understood and that they would receive the right care and treatment. When this was the case, they left the appointment feeling reassured about their health, and satisfied as a result.

Participant’s descriptions of unsatisfactory experiences were also consistent with previous research. Dissatisfaction corresponded to inaccessible communication prior to and during the appointment (Mastebroek et al., 2016), directing questions to carers more readily than, and in ways that excluded, the patient (Ziviani et al., 2004), failure to account for hearing and vision impairments (Wullink et al., 2009), and discontinuity of health professionals (Perry et al., 2014). Participants in the current study expressed frustration when they inferred a lack of ability or willingness to make

reasonable adjustments based on these experiences. For some this also extended to the physical design of the surgery and the presence or absence of assistive technology. Previous research describes how people with an intellectual disability may interpret such sources of dissatisfaction as a form of discrimination (Ali et al., 2013). Participants in the current study tended to view these factors as an indication that they, and their health, were not important to primary care staff.

In response, participants made efforts to ensure that they saw health professionals they felt comfortable with. Consistent with the previous literature, participants in this study preferred to see familiar professionals they were confident would treat them like a person (Perry et al., 2014). These professionals could only have become familiar and preferred because of satisfactory initial experiences. Previous literature highlights how a patient centred approach can reduce people with an intellectual disabilities experience of anxiety and uncertainty during health appointments (Flynn et al., 2016). The current study suggests that a patient centred approach, viewing the patient as a whole person with the intent of learning what they value, need, and prefer during consultations, may provide greater inclusion and reassurance for people with an intellectual disability (Casu et al., 2019).

Alternatively, participants enlisted the support of carers to help them manage barriers and achieve their health-related goals. In line with the existing literature, difficulties with communication (Chinn & Ruddall, 2019), memory (Perry et al., 2014), self-organisation, and using communication technology (Hanlon et al., 2018) were mentioned as barriers to arranging and attending the AHC. Carers were enlisted to varying degrees to help participants overcome these barriers. Similar to previous research (Perry et al., 2014), for those who required the least daily support their carers tended to take on a “*back up*” role and were there “*just in case*” (Rose, line 826). For those who required the most support, carers took a substantially more active role. Participant’s descriptions suggested that the more support they required, the more the experience became shared with their carer, which in turn could influence the participant’s experience. For example, both Carla and her mother appeared to share a general dissatisfaction with the way her AHCs were provided.

Alternatively, while Robert was very satisfied with his AHC experience, frustrations described by other participants were instead described by his carer.

Consistent with previous research (Perry et al., 2014) a given participant's satisfaction with a specific aspect of the process was often mirrored by another's dissatisfaction. Participants rarely described total satisfaction or total dissatisfaction. Instead, the experience flowed towards or away from the ideal of perfect inclusion. The findings suggest that this may be due to the range of accessibility issues participants experienced, emerging from the interaction of individual impairments and how they were asked to engage with the AHC process. As such they were unique and required a more considered approach to selecting appropriate reasonable adjustments.

Implications for Practice

Participant descriptions in the current study demonstrate how people with an intellectual disability may view the provision of reasonable adjustments, and how they influence the experience of inclusion, as indicators of quality and sources of reassurance. Their desire to see familiar health professionals may function to ensure their appointments are characterised by these experiences.

The study also demonstrates, in agreement with the previous literature, an overlap between the behaviours people with an intellectual disability cite as satisfying, and the principles of patient-centred care. Patient centred care is a core component of high-quality care (Casu et al., 2019) and has become a central part of the NHS constitution in the delivery of compassionate care (Brown et al., 2016). Even in the absence of specific training regarding people with an intellectual disability, interactions with health professionals demonstrating these principles have been described as more satisfying by this group (Flynn et al., 2016). The skills are also transferable across patient groups. It is recommended that all members of primary care staff are supported to develop these skills.

To properly assess the application of patient-centred care appropriate outcome measures are required. As described by previous literature, the current methods for assessing people with an intellectual disabilities satisfaction with primary care are unsuitable (Chapman et al., 2018). The current study suggests that satisfaction for people with a learning disability may be more focused on relational aspects and the experience of inclusion. The use of measures that focus on the assessment of both may be more suitable. Such measures may not exist, and this point is discussed further as a future research recommendation in the next section.

Specific to the development of patient-centred care, how reasonable adjustments are understood and applied in practice requires further attention. The presence or absence of reasonable adjustments add to or detract from the experience of an inclusive appointment by both increasing the cognitive burden on participants and reducing their ability to understand or recall what was discussed (Hanlon et al., 2018). The Equality Act 2010 (Perry et al., 2014) outlines the anticipatory duty of services to make reasonable adjustments that support equal access. Anticipatory refers to the fact that adjustments should be made both before people with an intellectual disability access services and on an ongoing basis. To ensure that adjustments are reasonable it is recommended that practices include a regular review by seeking feedback from their intellectually disabled patients. Such a review could be incorporated into the Annual Health Check appointment.

Limitations

All participants in the current study were recruited from self-advocacy groups. These groups exist to ensure that the voices of people with an intellectual disability are heard and considered by government and health officials. Promotion of the AHCs, and improving the experiences of healthcare more generally, have become an increasingly common priority of these groups. When considering the results of this study the reader should hold in mind that those who chose to participate may have done so because of strong opinions regarding the AHCs or primary care.

To reduce the risk associated with face-to-face interviews during the COVID-19 pandemic, data collection was restricted to remote interviews using video call software. It is acknowledged that this may have presented additional barriers to participation and recruitment.

In addition, all interviews took place between October 2020 and February 2021, spanning the second wave of the COVID-19 pandemic in the UK. Almost all participants specifically mentioned how their AHCs, if it had taken place between April 2020 and February 2021, had been impacted by the pandemic. These events offered participants and the researcher an additional experience with which to compare and contrast their typical AHC experience. This also meant that their most recent experience was not of a typical Annual Health Check.

Future Research Recommendations

Theme 1 describes the important finding that participants were motivated to attend AHCs based on a view that they were either beneficial or essential to their health. To the researcher's knowledge this has not been discussed in previous studies. Some participants saw health checks as a way to enhance their ability to stay healthy, while others were focused on preventing illness or premature death. These findings suggest that efforts to raise the intellectual disability community's awareness of health disparities may have unintentionally also raised the anxiety they experience regarding their health. In turn, this may have an influence on health check attendance. Future research may wish to explore if such a relationship exists, and if so, how it affects attendance.

That Scott stood apart from the other participants, by not expressing concerns about his health, and that he was overdue for a check, may further support this hypothesis. Anxiety towards healthcare, as expressed by Scott, has been linked to healthcare avoidance as a coping strategy within the general population (Byrne, 2008). Future research may wish to discern if this is a driving factor in the decision of some people with an intellectual disability not to attend offered health checks.

Themes 2 and 3 suggest that the experience of reasonable adjustments that successfully reduce barriers and sources of dissatisfaction relate to people with an intellectual disabilities experience of inclusion. Satisfaction is widely used as a proxy measure for the quality of health services. Future research may wish to address the need for suitable satisfaction measures in primary care for people with an intellectual disability. Such research may wish to adapt existing measures of patient centred care, for example the Provider-Patient Relationship Questionnaire (PPRQ, Casu et al., 2019).

Conclusions

To the authors knowledge this is the first study to seek a phenomenological understanding of what it is like for adults with an intellectual disability to go through the AHC process. This study adds a number of findings to the existing literature. The first is that people with an intellectual disability attend their AHC with specific goals related to their physical health, a desire to be actively included throughout, and with expectations about what constitutes a good health check. The second is that the fulfilment of these goals and expectations is reliant on the presence of reasonable adjustments, receptive and respectful primary care staff, and the person centred advocacy of a carer or family member. Third, *“being treated like a person”* and not like a diagnostic *“label”* appear to be indicators that people with an intellectual disability may look for in primary care staff to be reassured that their goals will be supported and that they will receive “the right treatment”. Not surprisingly, being listened to and valued rather than treated as a means to completing a “checklist” went a long way towards making the AHC a positive experience for the participants in this study. Finally, the study highlights the central role of primary care staff in the experience of the AHC for people with an intellectual disability and their satisfaction with it.

Taken together, these findings suggest that people with an intellectual disability have expectations of their AHC appointments, and that the satisfaction they experience is

dependent on the quality of their interactions with all primary care staff. Where they experience these interactions as inclusive and respectful they leave feeling heard, understood, reassured, and potentially more likely to return the following year. Where they experience these interactions as uncaring and excluding they leave feeling unimportant and frustrated. Such experiences are unlikely to encourage AHC attendance. Ensuring that a person-centred approach is adopted by all primary care staff in their interactions with their intellectually disabled patients may not only increase their satisfaction with each visit, it may also support increasing the uptake of AHCs among this population.

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Chapter 3: Reflective Paper

Reflections on the Experience of a Doctoral Thesis

This paper has not been for submission to a Journal

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Introduction

This chapter aims to provide a reflective account of parallel experiences as a trainee, a clinician and a novice researcher, and how they overlapped while completing a doctoral thesis. While there are many definitions and approaches to reflection, what's common is a focus on improving future action by critically examining past experience (Nicol & Dosser, 2016). Throughout training I've used John's (1995) tenth model of structured reflection as a guide to critically examining my practice and direct my professional development. The model provides questions that help the reflector to order their thoughts about the experience, and to explore what emerges as it emerges. It begins by encouraging the practitioner to write a description of the experience.

Describe the Experience

While the thesis as a document emerged from many experiences across the three years of training, a consistent feature of those experiences was a perceived pressure to perform. The thesis represents a significant milestone in my doctoral training. To quote a research supervisor "It's the assignment that gets you your doctorate". Each stage, from inception to completion, occurred alongside my journey as a trainee and my development to date as a clinician. At times I struggled to balance the competing demands in terms of the time and energy I felt was required. It's only while reflecting here that I've come to acknowledge just how much pressure I felt I was under and how much of it came from myself.

All of this happened in the context of a global pandemic. At the time the pressure I experienced drove me to keep going no matter what. Before March 2020 the original recruitment strategy for the empirical study had planned to involve NHS sites and key professionals, the cooperation of whom had already been secured. The original data collection strategy had also included additional visual resources to support the communication of participants with an intellectual disability. Following Coventry Ethics decision to preclude all but data-collection via remote means I had to redesign the recruitment and data collection methods of the study. This included a re-write of the ethics proposal and amendment of accessible study materials.

How does this connect with previous experiences?

Before the thesis I had experience of completing undergraduate and Master's dissertations which required me to develop a core set of academic skills. However, both the systematic literature review and empirical study confronted me with a succession of challenging firsts. I hadn't undertaken a piece of qualitative research before. I wasn't even aware of Interpretative Phenomenological Analysis (IPA) before it became the methodology for my empirical study. The same was true for meta-ethnography which became the basis for the systematic literature review. On reflection I wasn't prepared for the amount of work involved in conducting these forms of research and the steep learning curve I was about to step onto.

Both the first and second chapter of this thesis explore people with an intellectual disability's efforts to live healthier lives. Before training I spent 12 years working closely with intellectually disabled children and adults. In this time, I witnessed many examples of the barriers this group encounters when accessing services. As an Assistant Psychologist I supported General Practitioners (GP) while they delivered Annual Health Checks. My role was to support communication during these appointments. The experience suggested to me a need for better communication tools when the person with an intellectual disability does not use language. I noticed how difficult it was for the person to understand what was being asked of them by the GP, as well as the frustration it caused for everyone involved. This sometimes prolonged a person's treatment for ill health and prolonged their distress as a result. I started reading the existing literature looking for ways to improve communication within the Annual Health Checks. I was still reading this research when I started the doctorate. I realised this topic could represent a gap in the existing knowledge that the empirical chapter of the thesis could help to fill.

How did I feel?

The experience of completing the first two chapters of the thesis corresponded to a range of emotions. I felt overwhelmed by how much work I thought would be involved at each stage. And I felt uncertain about my ability to conduct either an empirical study or a systematic review. Changes due to the pandemic only added to the experience of uncertainty. I felt anxious about the stages that were beyond my immediate control, namely the recruitment and data collection stages of the empirical study. And I felt unprepared to use either

research methodology. With IPA in particular I wasn't sure I had the skills necessary to collect the required depth of experiential accounts.

During a bracketing discussion with a research supervisor we spoke about the imbalance of power that benefited me, in the short-term at least, more than the participants. By completing the study, I would gain what I required to complete my doctoral training. For any of the potential benefits described in the participant information sheet to return to those who took part it would be necessary to publish or otherwise disseminate the research findings. I felt a strong sense of moral responsibility and an ethical duty to produce a study of the best quality possible to maximise the chances of publication.

There was also the experience of contrast between the role of a clinician and that of a researcher. While a clinician works to effect change with those they support, a researcher seeks to learn and describe what exists without affecting change. In addition, while a clinician seeks to hold a wide view of the person and remaining open to reformulation as required, the researcher seeks to establish a refined perspective with a focal interest on new knowledge in a short window of time.

I was anxious when I first began interviewing participants for the empirical study. Qualitative research, similar to therapy, is unpredictable. Though the researcher defines the questions and the approach to data collection, they do not define the answers they receive from participants. I found the interview process both rewarding and exhausting. There were my own pre-understandings to remain mindful of while attending to the material being provided by the participant. There was also the time needed to reflect on interviews afterwards and the long process of transcription. Both depleted the energy and time I had available for other areas of training or my personal life. As the thesis progressed I felt the need to sacrifice more of my time with family and friends.

What was I trying to achieve?

In line with personal values concerning compassion, equity and fairness, I hoped that I would be able to produce research that gave health professionals an insight into what it felt like to receive an Annual Health Check. I hoped that this would extend to improvements in the experience for people with an intellectual disability. And I hoped that it would encourage more people to attend Annual Health Checks.

In completing a systematic review of this groups experiences of trying to live healthier lives I hoped to arrive at new insights that would help make those efforts easier and more successful.

At the same time, and in response to the uncertainty of conducting research, I tried to create certainty by discovering the 'right' process for applying each research methodology. This was an impossible task for two reasons. The first was that alongside clinical training and the completion of academic assignments I didn't have enough time, attention, or energy to achieve that level of understanding. The second was that the selected research methods were interpretative approaches, meaning that the level of understanding I desired could only come from the experiencing of doing that research.

The necessity and challenge of including people with an intellectual disability in research about their lives is well recognised (Carey & Griffiths, 2017). Specific to the empirical study, I also wanted to conduct it in an inclusive way. Inclusive research seeks to engage people with an intellectual disability so that they are not just the subject. The aim is instead to address issues that they identify as important, in ways that improve their lives and increases their voice within the literature (Hollomotz, 2018). Adults with an intellectual disability were included in an advisory role to inform the design of the study materials. Specifically, they were asked to critique the appearance, wording, and accessibility of those materials. This is the most common role that people with an intellectual disability take in inclusive studies (Bigby et al., 2014).

What were the consequences?

Previous reflective accounts while training have highlighted the presence and interaction of a fear of failure and unhelpful perfectionism. In my clinical work efforts to control or avoid this fear have led me to 'lean into' therapeutic work more than is helpful and attempt to 'fix' service users in order to reduce the distress I felt as a witness to their challenges. These behaviours connected to a lack of certainty about what 'being' a clinical psychologist or an effective therapist 'looked like'. Efforts to create certainty led to narratives equating effectiveness with 'being helpful' without further defining what 'helpful' would look like or how it fit within the wider aim of developing therapeutic competence.

A similar lack of certainty showed up while grappling with the experience of 'being' a novice researcher. The pressure I placed on myself was about controlling my fear of failing the doctorate. Unhelpful perfectionism emerged in the form of unworkable striving to satisfy extremely high standards. Recognition of these concerns allowed me to develop a more specific awareness of the unpleasant emotional experiences the thesis sometimes triggered - that I didn't know enough to be able to complete it to the high standards I had set for myself.

What knowledge did and should have informed me?

I knew that the quality of the thesis would determine whether I was awarded a doctorate. I knew that the thesis would be critically reviewed by an external examiner and that I would have to defend it during a clinical viva. I knew that I wanted to publish the research the thesis contained, particularly the empirical chapter. I wanted to live up to the hoped for aims of the study and the ethical duty I felt towards participants. And I wanted to try to make the experience of the Annual Health Check's better for people with a learning disability.

What I should have remembered were the articles I'd read while preparing my first clinical placement reflective account. Clinical Psychology training is inherently stressful due to the constant development trainees undergo (Jones & Thompson, 2017). However, adding to that stress by striving for perfection has at times pushed my arousal above the optimal threshold for learning (Kreutzer et al., 2011). Previous research indicates that the completion of a doctoral thesis can coincide with the experience of stress, exhaustion, and unpleasant emotional states (Stubb et al., 2012). It is typical for clinical psychology trainees to respond to that stress by seeking to excel (Stafford-Brown & Pakenham, 2012).

Throughout training I have found Acceptance and Commitment Therapy (ACT) to be a personally meaningful and effective way of reflecting on the difficult experiences I've encountered. In each case the model has helped me to understand the root of my struggling and discern more workable ways of moving towards my chosen values. Had I been using it to understand my experiences as a researcher I may have noticed the experiential avoidance and unworkable striving I was choosing.

ACT distinguishes the experience of psychological pain from the experience of psychological suffering (Hayes, 2020). While the former is viewed as inevitable, the latter is considered

optional in that it results from behavioural choices intended to control or avoid psychological pain (French et al., 2017). That doctoral training and the completion of a thesis would be a stressful experience is likely something that cannot be avoided. And though it is an intense experience it is meant to prepare me for work as a clinical psychologist after I qualify. What was optional was the degree to which I struggled with that stress, and choose to expend energy and time in unworkable ways.

Could I handle this better in the future?

ACT provides a path out of suffering by supporting people to increase 'psychological flexibility' and reduce 'experiential avoidance' (Tracey et al., 2018) through six processes of change (Hayes et al., 1999). These processes aim to raise a person's awareness of the external environment; the intended function of private mental events and self-rules derived from experiences; the outcomes and workability of past behaviour based on derived rules; and the selection of future workable behaviours that are less rigid in the pursuit of chosen values (Hoffmann et.al., 2016).

Reflecting now on my research experiences, pressure, fear and responsibility were not the only emotions that showed up. After my intellectual disability core placement, I was reminded of how much I enjoy working with this group of people. It connects me to values of equity, inclusion and empowerment and joyful experiences of a type that I don't encounter as often or to the same degree when working with other clinical groups. I can recall now that there were many moments like this as I was completing the thesis. I felt excited to have the opportunity to produce new knowledge with the potential to improve the lived experience of people with an intellectual disability. I also felt encouraged and grateful for the interest that people with an intellectual disability expressed towards the empirical project during its development, recruitment, and data collection stages. There was so much interest that by the end I had more people wanting to take part than I had time to interview. I was also struck by how willing each participant was to share their experiences with me. To my surprise most of the interviews approached 90 minutes. This suggested to me that the subject I had chosen was one that mattered a great deal and that people had been waiting for the opportunity for their voice to be heard.

Being able to make sense of a doctoral thesis in ways that make it meaningful beyond passing or failing have been shown to moderate associated stress (Stubb et al., 2012). From

an ACT perspective this doesn't just mean identifying the values that motivate the thesis in its entirety (Hayes, 2019). It also means noticing and choosing small, everyday opportunities to enact those values. In every interview I was able to enact values of compassion and equity by the way that sought participants views and communicated to them that their experiences mattered.

I could have supported myself better by bringing my attention to advice offered to me by my academic tutor in my first year. He described research as the making and addition of a single brick to an existing structure of knowledge. Holding onto this metaphor frames the thesis, and any subsequent research I may conduct as an effort to take a small step slowly.

Can I support myself better as a result?

This experience has taught me to approach research in the same manner I've been learning to approach therapy, as a learning experience. Holding a view of the thesis as a learning process, which is what it's intended to be, would have reduced the impact of the difficult self-judgments and fears that showed at each step along the way.

The final stage of the research, that of dissemination, is another opportunity to move towards the ideals of inclusive research and one which I intend to pursue. Each of the self-advocacy groups that supported the recruitment to the empirical study also asked if I would come back when the study was completed and share my results. I plan to contact them again once the thesis has gone through the viva process and I'm ready to think about publication. The findings of both the systematic and empirical paper suggest that this population is eager to engage in such a dialogue so as to be better understood. My impressions of each self-advocacy group was that of people motivated to change their world for the better. In line with the value of empowerment I'm eager to share these research findings, learn what they think and, witness what they may choose to do with that information.

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Appendices

Appendix 1.1: Full list of search terms used in systematic literature search

Intellectual disability and healthy lifestyle

("learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*") AND ("health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*") AND (interview OR "focus group" OR "mixed metho*" OR qualitative) AND (attitude OR experience OR belief OR view) AND ("mixed metho*" OR qualitative)

Intellectual disability and physical activity

("learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*") AND ("health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*") AND (exercis* OR fitness OR active* OR "physic* activ*" OR cardi* OR "cardi* fitness") AND (interview OR "focus group" OR "mixed metho*" OR qualitative) AND (attitude OR experience OR belief OR view) AND ("mixed metho*" OR qualitative)

Intellectual disability and healthy eating

("learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*") AND ("health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*") AND (diet OR "health* diet" OR "health* eating" OR "balanced diet" OR nutrition* OR "nutritional intake" OR "nutrient balance" OR "calor* reduction" OR "calor* restriction" OR "fresh produce" OR fruit* OR vegetable* OR fibre OR fat OR sugar OR "junk food" OR "high-fat foo*" OR "sugary foo*" OR "sugary drinks" OR "soft drinks" OR "saturated fat" OR "fatty foo*") AND (interview OR "focus group" OR "mixed metho*" OR qualitative) AND (attitude OR experience OR belief OR view) AND ("mixed metho*" OR qualitative)

Intellectual disability and alcohol consumption

("learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*") AND ("health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*") AND ("reduc* alcohol" OR "sto* alcohol" OR alcohol OR "lowering alcohol") AND (interview OR "focus group" OR "mixed metho*" OR qualitative) AND (attitude OR experience OR belief OR view) AND ("mixed metho*" OR qualitative)

Intellectual disability and smoking tobacco

("learning disab*" OR "intellect* disab*" OR "development* disab*" OR "intellect* and development* disab*" OR "ment* retar*") AND ("health* li*" OR "health* li* behav*" OR "health* behav*" OR "health promot* behav*") AND ("reduc* smoking" OR "sto* smoking" OR smoking OR cannabis OR marijuana OR "soft drugs") AND (interview OR "focus group" OR "mixed metho*" OR qualitative) AND (attitude OR experience OR belief OR view) AND ("mixed metho*" OR qualitative)

Appendix 1.2: Critical Appraisal Skills Program Tool



Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
 - why it was thought important
 - its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
 - Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 1.3: The 7 stages of conducting a meta-ethnographic review

Table 1 The seven phases of Noblit and Hare's meta-ethnography approach

Phase	Noblit and Hare's description
Phase 1: Getting started	'Identifying an intellectual interest that qualitative research might inform' ([15], p.26). The focus of the synthesis may be revised through reading interpretive qualitative studies.
Phase 2: Deciding what is relevant to the initial interest	Study selection should be 'driven by some substantive interest derived from comparison of any given set of studies' ([15], p.28). Searches for studies need not be exhaustive: 'unless there is a substantive reason for an exhaustive search, generalizing from all studies of a particular setting yields trite conclusions' ([15], p.28).
Phase 3: Reading the studies	The repeated reading of studies and noting of metaphors with close attention to details in the studies and what they tell you about your area of interest ([15], p.28).
Phase 4: Determining how the studies are related	Noblit and Hare recommended that reviewers create 'a list of key metaphors, phrases, ideas and/or concepts (and their relations) used in each account, and [to] juxtapose them' ([15], p.28) in order to make an initial assumption about how the studies relate to one another. This informs the type of synthesis that will be carried out – a reciprocal or refutational translation or line of argument synthesis.
Phase 5: Translating the studies into one another	The metaphors and/or concepts in each account and their interactions are compared or 'translated' within and across accounts while retaining the structure of relationships between central metaphors/concepts within accounts. The translations taken together are 'one level of meta-ethnographic synthesis' ([15], p.28). These are systematic comparisons and reciprocal translation is key to a meta-ethnography.
Phase 6: Synthesising translations	If there are many translations from phase 5 these can be compared with one another to see if there are common types of translations or if some translations or concepts can encompass those from other studies. 'In these cases, a second level of synthesis is possible, analyzing types of competing interpretations and translating them into each other' ([15], p.28) to reach new interpretations/conceptual understandings.
Phase 7: Expressing the synthesis	Tailoring the communication of the synthesis to the intended audience's culture and language so that it is intelligible and meaningful to them - 'the written synthesis is only one possible form' ([15], p.29).

France et al., 2014, p.3

France, E. F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., & Jepson, R. (2014). A methodological systematic review of what's wrong with meta-ethnography reporting. *BMC medical research methodology*, 14(1), 1-16. <https://doi.org/10.1186/1471-2288-14-119>

Appendix 1.4: Example data extraction table for Brooker et al., 2015

Study title: “We Can Talk While We’re Walking”: Seeking the Views of Adults With Intellectual Disability to Inform a Walking and Social-Support Program

Objective: The aim of the interviews was to better understand the views of potential participants, both people with intellectual disability and volunteers, about walking and social support.

Themes: Careful consideration of the interviews uncovered a range of factors that have the potential to mediate participation in physical activity and inform the implementation of the program. These factors were classified under three broad themes: individual factors that facilitated activity but sometimes arose as barriers, external factors that were barriers to participation, and broader normative factors that directed participation.

- | | | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>A. Individual factors that were facilitators and sometimes barriers to participation</p> <p>A.1 Walking for health</p> <p>A.2 Walking with others: Opportunities for social connections</p> <p>A.3 Walking it off: The emotional benefits of walking</p> | <p>A.4 Walking environments: Being outside</p> <p>B. External factors that were barriers to participation</p> <p>B.1 Avoiding discomfort and stress</p> <p>B.2 Environmental factors affecting walking</p> <p>B.3 Feeling safe</p> | <p>C. Broader normative factors</p> <p>C.1 Norms of safety</p> <p>C.2 Perceptions of disability: Duty of care</p> <p>C.3 Perceptions of self-ability: Limitations of body</p> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Themes & Participant Quotes	Primary Author Interpretations	Reviewing Author Interpretations
A. Individual factors that were facilitators and sometimes barriers to participation	Individual factors that could frequently act as facilitators for participation in physical activity included participants’ understanding of the role walking played in their health, opportunities for social connections, the emotional benefits derived from walking, and being able to walk in their preferred environment.	These individual factors relate to short and long-term reinforcers/motivators for walking.
A.1 Walking for health “I like walking ‘cause it gives you more exercise and helps your heart” (female, participant, mid-50s). “Some mornings I do a little power walk up the hill. Just gets the heart going” (male participant, mid-30s).	For the majority of participants dominant health-promotion messages around exercise, eating well, and drinking plenty of water were clearly evident in their understanding of being healthy. Within this, walking was seen as a key contributor to maintaining health:	Health promotion messages in included quotes from PWID referenced how walking as a form of PA supported heart health and weight loss.

Appendix 1.5: CASP quality appraisal scores

Paper	Vlot-van Anrooij et al., 2020		Salomon et al., 2019		Leser et al., 2018		Kuijken et al., 2016		Caton et al., 2012		Dixon-Ibarra et al., 2016	
Rater	1	2	1	2	1	2	1	2	1	2	1	2
CASP Questions												
Q.1	2	2	2	2	2	2	2	2	2	2	2	2
Q.2	2	2	2	2	2	2	2	2	2	2	2	2
Q.3	2	2	0	1	0	0	0	1	0	1	1	2
Q.4	2	2	1	1	2	2	2	2	2	2	1	1
Q.5	2	2	2	2	2	2	2	2	2	2	2	2
Q.6	1	1	0	0	0	0	1	1	1	0	1	1
Q.7	2	2	2	2	2	2	1	1	1	1	1	1
Q.8	2	2	1	1	1	1	2	2	1	1	2	1
Q.9	2	2	1	1	2	2	2	2	2	2	2	2
Q.10	2	2	1	1	2	2	2	2	2	2	1	1
Total (out of 20)	19	19	13	13	15	15	16	17	16	15	16	15
Score (%)	95	95	65	65	75	75	80	85	80	75	80	80

Paper	Taliaferro & Hammond, 2016		Brooker et al., 2015		van Schijndel-Speet et al., 2014		Doherty et al., 2018		Gee et al., 2020		Kerr et al., 2017	
Rater	1	2	1	2	1	2	1	2	1	2	1	2
CASP Questions												
Q.1	2	2	2	2	2	2	2	2	2	2	2	2
Q.2	2	2	2	2	2	2	2	2	2	2	2	2
Q.3	1	2	1	1	1	2	1	1	2	2	2	2
Q.4	1	1	1	1	1	1	2	2	1	1	2	2
Q.5	2	2	1	2	2	2	1	2	1	1	2	2
Q.6	0	0	1	1	0	1	1	1	2	2	0	0
Q.7	1	1	2	2	1	1	2	2	1	1	1	1
Q.8	1	2	2	2	1	2	2	2	1	1	1	1
Q.9	2	2	2	2	2	2	2	2	2	1	2	2
Q.10	2	2	2	2	2	2	2	2	1	1	1	2
Total (out of 20)	14	16	16	17	14	17	17	18	15	14	15	16
Score (%)	70	80	80	85	70	85	85	90	75	70	75	80

Appendix 1.6 – Inter-rater reliability coefficient (Kappa) statistic

Study	K Value	Approximate Significance (<i>p</i> value)
Vlot-van Anrooij et al., 2020	1.000	.002
Salomon et al., 2019	.839	.000
Leser et al., 2018	1.000	.000
Kuijken et al., 2016	.778	.003
Caton et al., 2012	.808	.003
Dixon-Ibarra et al., 2016	.600	.058
Taliaferro & Hammond, 2016	.643	.005
Brooker et al., 2015	.808	.003
van Schijndel-Speet et al., 2014	.630	.020
Doherty et al., 2018	.737	.016
Gee et al., 2020	.800	.010
Kerr et al., 2017	.804	.001
Total	.789	.000

Appendix 1.7 - Sample of phase 4 of the meta-ethnographic approach, determining how the studies are related, employed in the systematic literature review

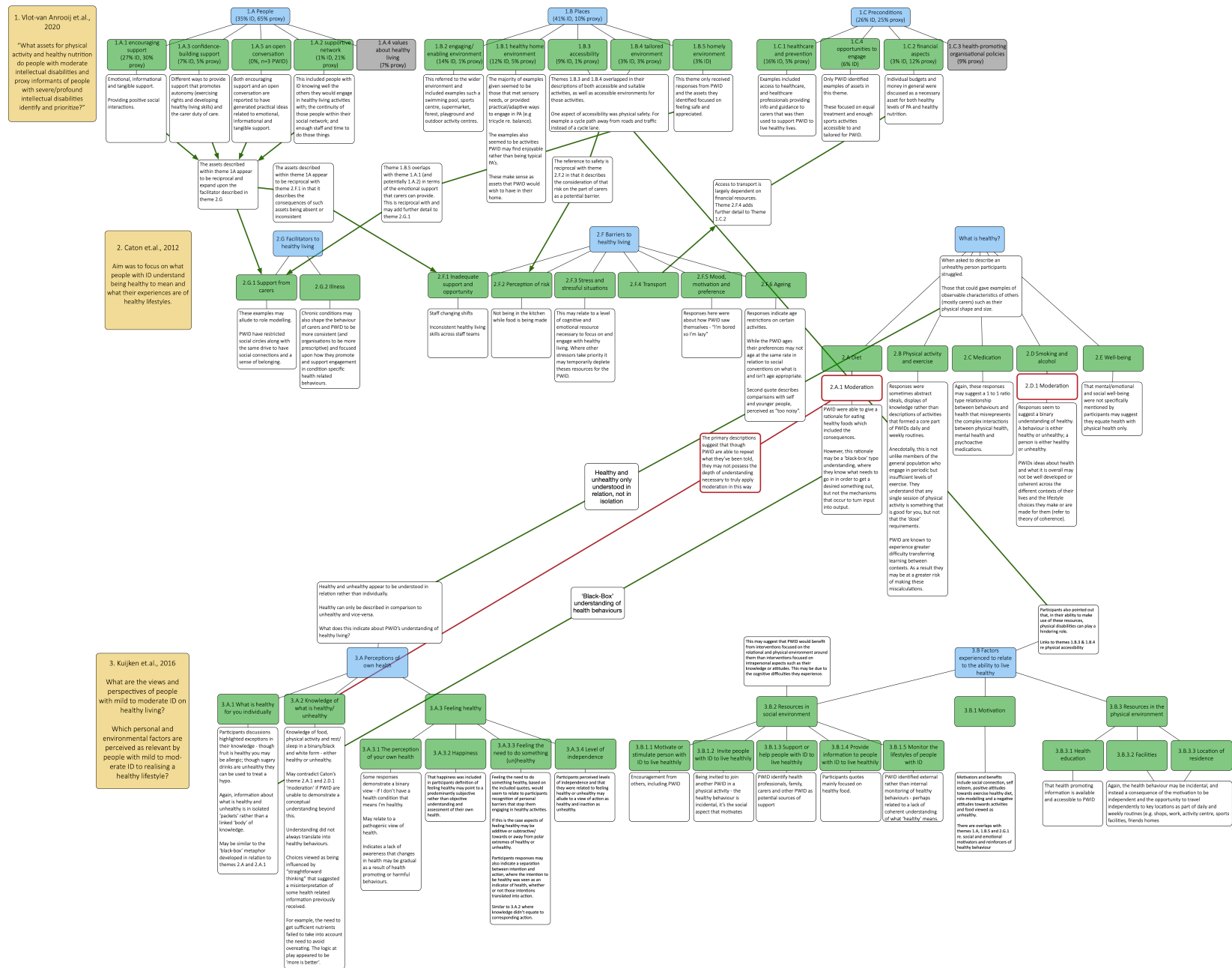


Diagram Key

Yellow boxes - Study authors and aims.

Blue boxes - themes from included studies.

Green boxes - sub-themes from included studies that are based on contributions from participants with an intellectual disability.

Grey boxes - sub-themes from included studies that are not based on contributions from participants with an intellectual disability.

White boxes - initial interpretations by current author of participant contributions, first author interpretations and how they may be related between studies.

Green lines - themes that are shared or are similar between studies. These connections may form the basis of a reciprocal synthesis.

Red lines - themes that contradictory or may indicate differences between studies. These differences may form the basis of a refutational synthesis.

Appendix 2.1: Accessible invitation to participate



My name is Andrew. I am a Trainee Psychologist.

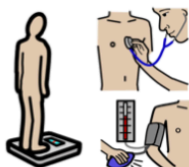
I would like your help with a study.

A study to find out what it is like to have an Annual Health Check.



An Annual Health Check is for people with a learning disability.

It happens with your Doctor once a year.



People with a learning disability need more help to stay healthy.



Annual Health Checks help people with a learning disability stay healthy.



Using video chat I would like to interview people and ask:

- what it's like to have an Annual Health Check
- what's good about Annual Health Checks
- what would make Annual Health Checks better



You can show this letter to someone you trust.

You can bring someone you trust to the interview.



If you want to be in this study or find out more you can call, text or message me on WhatsApp. My number is **07915 944 329**.



Thank you for reading this letter.

Yours sincerely,

Andrew Bodel

Trainee Psychologist

Appendix 2.2: Participant Information Sheet (PIS)

2.2.1 versions of the PIS using accessible text with corresponding pictures

Participant Information Sheet



Hello, my name is Andrew. I am a Trainee Psychologist at Coventry University.

You are being asked if you want to help me learn what it is like to have an Annual Health Check.



Before you decide you should read this Participant Information Sheet carefully.

It will tell you why I am doing the study and what will happen if you take part.



You can show this Participant Information Sheet to someone you trust.

You can ask them to help you decide if you want to take part in the study.



If you choose to be in the study sign the consent form.

If you want someone to be with you when you talk to Andrew ask them to sign the consent form too.

Keep this Participant Information Sheet and the consent form somewhere safe.



1. What is the study for?

Andrew wants to know what it is like for you to have an Annual Health Check.



2. Why have you been asked to be in the study?

You are being asked to take part because:

- you have a learning disability
- you have had an Annual Health Check

3. What might be good about being in the study?

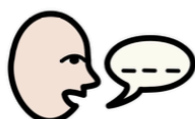
Taking part can:



- help people know what you think and feel about Annual Health Checks



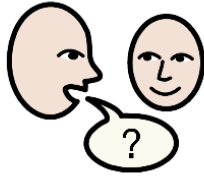
- help Doctors and Nurses know what it's like to have an Annual Health Check



- help people with a learning disability talk about their Annual Health Checks



- help make Annual Health Checks better



You might have questions about your Annual Health Checks.

Andrew can help answer your questions.

4. What might not be good about being in the study?



Talking about seeing the Doctor can make some people feel upset.



You might feel nervous about being recorded.

After the interview you might worry about what you said.

You might worry about other people reading what you said.



5. Is it safe for you take part in the study?

Coventry University's ethics team say this study is safe.

It's their job to make sure a study is done properly and safely.

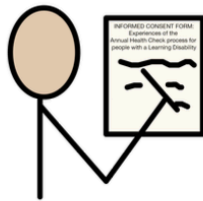
6. Do you have to take part in the study?

No. It is your choice.



You don't have to be in the study if you don't want to.

The choice you make will not change the help you get from your Doctor or anyone else.

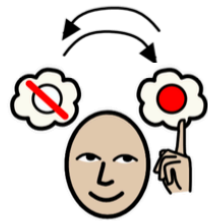


If you choose to take part please fill in the consent form.

If you want someone to be with you when you talk to Andrew ask them to sign the consent form too.

Keep these pages the consent form and your participant number safe.

7. What if you change your mind?



You can change your mind:

- before the interview
- in the interview
- after the interview

You don't have to say why you changed your mind.



If you change your mind call Andrew on 07915 944 329.

Tell Andrew your participant number.

He will take what you said out of the study.

8. What will happen if you choose to take part in the study?



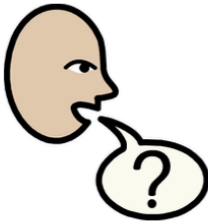
You and Andrew will talk using video chat.

You will be able to see and talk to Andrew.

Andrew will be able to see and talk to you.

The interview will be recorded.

Andrew will ask you questions about your Annual Health Check to find out:



- what it's like for you to be invited
- what it's like for you to be in the appointment
- what it's like for you after the appointment

You don't have to answer a question if you don't want to.



You can have someone you trust with you for the video chat.

At the start Andrew will check:

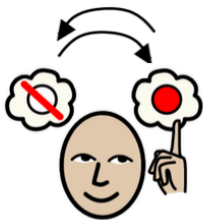


- you are happy to be interviewed
- you are happy to be recorded
- that you are in a quiet and private place
- that anyone helping you is happy to be recorded too

The interview will last for 1 hour. You can have a break anytime you ask.



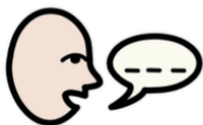
You can stop the interview at anytime.



You can change your mind at anytime.

It's your choice. You don't have to say why.

At the end of the interview Andrew will check:



- that what he has learned from you is right
- that what you said can be used in the study

9. What will happen to what you say?

Only Andrew will watch the recording. Andrew will write down exactly you both said.



Andrew will write about your age and learning disability.
Andrew will then delete the recording.

Andrew will change your name. Andrew will change the name of any people or any places you said. No one will know they are your words.

Andrew will use what you say to help other people know:



- what was good about having an Annual Health Check



- what wasn't good



- how it could be better



Andrew will share what he writes in a journal.

This is a magazine people read to learn to be better at their job.



Andrew will share what he writes at a conference.

This is a meeting where people learn new things.



How will what you say be kept private and safe?

Andrew will keep what you say private and in a safe place.



Andrew will follow the rules in the General Data Protection Regulation and the Data Protection Act.

These laws tell Andrew how to keep what you tell him private and safe.



Andrew will keep everything in a safe place.

Only Andrew will have the key to the safe place.

What if you want to complain?



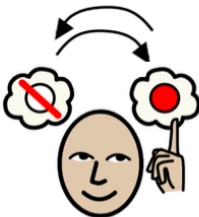
If you are unhappy when talking to Andrew you can tell him.



You can stop.

You can take a break.

You can choose to talk to Andrew another day.



You can change your mind and leave the study. It's your choice.



You can complain if you are unhappy with how Andrew behaved.

You can complain to the study supervisor.

His name is Anthony Colombo.

You can e-mail Anthony on a.colombo@coventry.ac.uk

Appendix 2.2.2: versions of the PIS using only the accessible text

Experiences of the Annual Health Check process for people with a Learning Disability

PARTICIPANT INFORMATION SHEET

You are being asked to help Andrew learn what it is like to have an Annual Health Check. Andrew is a Trainee Clinical Psychologist at Coventry University. Before you decide if you want to take part you should read this Participant Information Sheet. It will tell you why Andrew is doing the study. It will tell you what will happen if you take part. Please read this carefully. Ask Andrew if you are not sure about anything you read.

What is the study for?

Andrew wants to learn what it is like for you to have an Annual Health Check.

Why have you been asked to be in the study?

You are being asked to take part because:

- * you have a learning disability
- * you have had an Annual Health Check

What might be good about being in the study?

Taking part can:

- Help people know what you think and feel about Annual Health Checks
- Help Doctors and Nurses know what it's like to have an Annual Health Check
- Help people with a learning disability talk about their Annual Health Checks
- Help make Annual Health Checks better

You might have questions about your Annual Health Checks. Andrew can help answer your questions.

What might not be good about being in the study?

Talking about seeing the Doctor can make some people feel upset. You might feel nervous being recorded. After the interview you might worry about what you said. You might worry about other people reading what you said.

Is it safe for you take part in the study?

Coventry University's ethics team say this study is safe. It's their job to make sure a study is done properly and safely.

Do you have to take part in the study?

No. It is your choice. You don't have to be in the study if you don't want to. The choice you make will not change the help you get from your Doctor or anyone else.

If you choose to take part please fill in the consent form. Keep these pages the consent form and your participant number safe.

What if you change your mind?

You can change your mind before, during and after the video chat interview. You don't have to say why you changed your mind.

If you change your mind call Andrew on 07915 944 329. Tell Andrew your participant number and that you changed your mind. He will take what you said out of the study. You can change your mind until March 2021. This is when the study ends.

What will happen if you choose to take part in the study?

Andrew will ask you questions about your Annual Health Check to find out:

- what it's like for you to be invited
- what it's like for you to be in the appointment
- what it's like for you after the appointment

You don't have to answer a question if you don't want to.

You and Andrew will talk using video chat. You will be able to see and talk to Andrew.

Andrew will be able to see and talk to you. The interview will be recorded. The interview will last for 1 hour.

At the start Andrew will check:

- you are happy to be interviewed
- you are happy to be recorded
- that you are in a quiet and private place
- that anyone helping you is happy to be recorded

You can have a break at anytime. You can stop the interview at anytime. You can change your mind at anytime. It's your choice. You don't have to say why.

At the end Andrew will check

- * that what he has learned from you is right
- * that what you said can be used in the study

What will happen to what you say?

Only Andrew will watch the recording. Andrew will write down exactly you both said.

Andrew will write about your age and your learning disability. Andrew will then delete the recording.

Andrew will change your name and the names of any people or any places you said. Andrew will do this to make sure no one will know they are your words.

Andrew will use what you say to help other people learn:

- what was good about having an Annual Health Check
- what wasn't good
- how it could be better

Andrew will share what he writes in a journal. This is a magazine people read to learn to be better at their job. Andrew will share what he writes at a conference. This is a meeting where people learn new things.

You can have a copy of the study when it's finished.

How will what you say be kept private and safe?

Andrew will keep what you say private and in a safe place. Andrew will follow the rules in the General Data Protection Regulation and the Data Protection Act. These are laws that help Andrew keep what you tell him private and safe.

All electronic data will be stored on a password protected Microsoft OneDrive online storage account.

Your consent information will be kept in a different place from what you tell Andrew to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction and all collected data will be destroyed on or before the 1st of October 2026.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. This means they will keep your information private and safe.

You have the right to see what is written about you. The General Data Protection Regulation and the Data Protection Act 2018 are laws that say you can ask to see whatever is written about you.

You also have the right change what is written about you if it is wrong; to ask for information about you to be deleted, to choose how what is written about you is used and to objection, and to take back what is written about you.

For more details, including the right to make a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What if you want to complain?

If you are unhappy when talking to Andrew you can tell him. You can stop. You can take a break. You can choose to talk to Andrew another day. You can change your mind and leave the study. It's your choice.

You can make a complaint in writing to Andrew by e-mail at bodelj@uni.coventry.ac.uk

You can complain to the study supervisor if you are unhappy with how Andrew behaved.

The study supervisor is Dr Anthony Colombo. You can write to Anthony by e-mail at a.colombo@coventry.ac.uk

In your e-mail please tell Anthony about the study, that it is Andrew's study and why you want to complain.

Appendix 2.2.3: versions of the PIS using the standard language of the PIS template provided by Coventry University Ethics

Experiences of the Annual Health Check process for people with a Learning Disability

PARTICIPANT INFORMATION SHEET

You are being invited to take part in research into the experience of the Annual Health Check (AHC) process from the perspective of people with a learning disability (LD). The lead researcher, Andrew Bodel, is a Trainee Clinical Psychologist at Coventry University. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to explore the lived experience of receiving an AHC from the perspective of people with a LD. The study hopes to gain an understanding of these experiences in terms of:

1. the range of meanings participants voice in terms of their thoughts, emotions and beliefs
2. the role that others (e.g. carers and health professionals) play in shaping these thoughts, emotions and beliefs
3. the potential facilitators and barriers experienced while attending the AHC; and

Why have I been chosen to take part?

You are being asked to take part because you have a learning disability; you normally manage your interactions with your Doctor with or without support; you have had at least one Annual Health Check, and you can tell me what this was like for you during a web-based video-conference interview.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping Andrew and Coventry University to better understand what people with a LD think and feel about Annual Health Checks.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure.

Talking about seeing the Doctor can make some people feel upset. If you feel uncomfortable or unhappy at any time you can choose to stop the interview. You will be asked if you would like to take a short break, to reschedule the interview for another day or to withdraw from the study. It's your choice and you will not be asked to provide a reason for your choice.

Some people may feel nervous being recorded and they may worry that other people will read what they said and be able to identify them.

Only Andrew will watch the recording. The recording will be transcribed verbatim, with your name and the names of any people or any places you said changed so as to prevent others from identifying you. Andrew will do this to make sure no one will know they are your words. Andrew will then delete the recording.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate.

Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. You are free to withdraw your information from the project data set at any time until the end of March 2021 at which time the project will have been completed and submitted. However, it should be noted that after 2 weeks the interview will have been transcribed and the recording deleted.

You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study.

To withdraw, please contact the lead researcher on 07915 944 329 or via e-mail on bodelj@uni.coventry.ac.uk . Please also contact the Research Support Office (hls.rso@coventry.ac.uk; telephone +44 (0)24 7765 8718) so that your request can be dealt with promptly in the event of the lead researcher's absence.

You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked a number of questions regarding what it is like for you to have an Annual Health Check. The interview will take place via a web-based video conference. You will be able to choose a space and time that is convenient to you. The interview will be video recorded (and will require your consent for this and the consent of anyone else who may be supporting you during the interview), so the location should be in a fairly quiet area. The interview should take around 1 hour to complete. At any time during the interview you can choose to stop the interview. You can choose to take a short break, to reschedule the interview for another day or to withdraw from the study. It's your choice and you will not be asked to provide a reason for your choice.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team.

All electronic data will be stored on an encrypted and password-protected Microsoft OneDrive storage account held by Coventry University.

Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. Coventry University will take responsibility for data destruction and all collected data will be destroyed on or before October 2026.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018.

You also have other rights including rights of correction, erasure, objection, and data portability.

For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher, Andrew Bodel by e-mail on bodelj@uni.coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please write to Dr Anthony Colombo, Research Director in Clinical Psychology, by e-mail on a.colombo@coventry.ac.uk

In your e-mail please provide information about the research project, specify the name of the researcher and/or your research number, and detail the nature of your complaint.

Appendix 2.3: Informed consent form

Participant
No.

INFORMED CONSENT FORM:

Experiences of the Annual Health Check process for people with a Learning Disability

You have been asked to help Andrew learn what it is like to have an Annual Health Check. Before you decide if you want to take part you should read the Participant Information Sheet.

You can ask Andrew questions if you need to. It's important that you understand what will happen if you take part. It's your choice. You don't have to take part if you don't want to.

If you want to take part you need to show you agree with the sentences below. To show you agree you need to circle "yes". If you don't agree you need to circle "no".

If you circle every "yes" that means you want to take part. If you circle one or more "no" that means you don't want to take part.

If you want to take part in the study please sign your name in the participant box at the end of this form.

If you want someone you trust to be with you when you meet Andrew please ask them to read the Participant Information Sheet and sign their name in the supporting persons box at the end of this form.

1	I have read the Participant Information Sheet for this study. I have been able to ask any questions I had.	YES	NO
2	I know I don't have to take part if I don't want to. I know I can change my mind if I want to. I know I don't have to say why if I don't want to. I know I can ask Andrew to delete what I tell him. I know I can do this until March 2021.	YES	NO
3	I have written down my participant number (top left corner of this page) in a safe place. I know that I need this number if I change my mind.	YES	NO

4	I know that anything I say will be kept safe and private.	YES	NO
5	<p>I am happy for my words to be:</p> <ul style="list-style-type: none"> • used to help others understand what Annual Health Checks are like • shared in a journal. I am happy for my words to be • shared in a presentation <p>I know that no one will know they are my words.</p>	YES	NO
6	I am happy for the interview to be <u>video recorded</u>	YES	NO
7	Anyone supporting me during the interview is happy to be <u>video recorded</u>	YES	NO
8	I agree to be contacted and asked about the study results	YES	NO
9	I agree to take part in the above study	YES	NO

Thank you for your participation in this study. Your help is very much appreciated.

Participant name	Date	Signature
Supporting Person name	Date	Signature
Researcher name	Date	Signature

Appendix 2.4: Semi-structured interview guide

Thesis Interview Schedule

1. Helping Participants Feel at Ease

- There are no wrong answers. I want to know what it's like for you to have an Annual Health Check.
- You can tell me as much as you want. This is like a conversation but where you're in charge.
- You might see me write things down. This is to remind me of what you said and to ask questions about some of what you said.
- This meeting is to find out what it's like for you to have an Annual Health Check.

Overall questions (to be referred back to as necessary)

- Have you had many Annual Health Checks?
-
- What is it like to have an Annual Health Check?
- What help, if any, do you need during your Annual Health Check?

2. Beginning the Interview – background information

- When was your last Annual Health Check? Have you had many before?
- What did you think about/how did you feel about Annual Health Checks?
- Have you had good/bad Annual Health Checks before?
 - What's the difference between a good and a bad Health Check?
 - What's it like for you when you have a good/bad health check?

3. The Invitation Letter

- How do you know when it's time for your Annual Health Check?
- How do you arrange the check when it's time?
 - How are you invited?
 - What is it like to be invited that way?

- Does being invited in that way change what you think/feel about your Doctor?
- Do you get help to make the appointment? What is that like for you?

4. Before the Appointment

- On the day of the appointment do you do anything to get ready for your Health Check?
 - Does anyone help you to get ready?
 - Does their help make it easier/harder?
- Before going to the Doctors on the day how do you feel?
- When you get to the Doctors on the day how do you feel then?
- What is it like for you to be inside your Doctors surgery? (impact of environment and staff interactions).
- Before you go in do you know what will happen in your Health Check?
 - How do you feel about that?

5. The Health Check

- How do you feel when you go into see the Doctor/Nurse to have your Health Check?
- What is it like to talk with the Doctor/Nurse?
 - Do you like your Doctor/Nurse? Do you feel comfortable/uncomfortable with them?
- Does someone go in with you to your Health Check?
 - Does their help make it easier/harder?
- What happens when you have an Annual Health Check?
 - Are there different parts to your Health Checks?
 - What would you call these parts?
 - How do you feel about these parts?

6. After the Health Check

- How do you feel when you leave the Doctor/Nurses room after your Annual Health Check?

7. Ending the Interview

- Is there anything else you want to tell me about what it is like for you to have an Annual Health Check?

Appendix 2.5: Accessible debrief letter



Thank you for being in the study.

I hope our meeting will help make the Annual Health Checks better.

I hope this will help more people have an Annual Health Check.

What happens next?

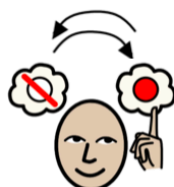


I will keep what you said private and safe. I will **not** use your name.



I will write down exactly what we said and delete the video.

I will change some of what you said so that no one knows they are your words.



What if you worry about what you said?

After today you can still change your mind. You can change your mind until (appropriate date).



You can call me on 07915 944 329.

You can tell me to delete some or all of what you said.

You don't have to tell me why you changed your mind.



Thank you for meeting with me today.

Yours sincerely,

Andrew Bodel

Trainee Psychologist

Appendix 2.6: Readability statistics of all study materials

The readability of all materials used for recruitment and data collection were assessed using Flesch Reading Ease readability scores and the Flesch-Kincaid grade level test. Both were applied through Microsoft Word. Both are widely used measures of a document's accessibility. Higher Flesch index scores indicate greater readability, whereas higher grade level scores indicate poorer readability. Flesch readability is also a good proxy for ease of understanding when questions are read aloud. The Flesch–Kincaid Reading Ease score is based on the average number of words per sentence, the number of syllables per word and the use of a passive tone. A score of 90–100 is considered easily understandable by an average 11-year-old, a score of 60–70 is considered easily understandable by 13- to 15-year-olds and a score of ≤ 30 is considered easily understandable by graduates. The Flesch–Kincaid Grade Level score rates text in terms of US school years: a score of 8.0 means that an eighth-grade student (aged about 13 years) would be able to understand the information. Below are the readability scores for each document developed for the study. In the United Kingdom and within the National Health Service (NHS) efforts to make information accessible are described as 'easy read'. A document is considered 'easy read' if it achieves a Flesch-Kincaid Grade score of 3 or below.

Document	Flesch readability score	Flesch-Kincaid Grade
Accessible Invitation Letter ver. 5	80.9	3.9
Accessible social media poster	89.8	3.2
Accessible recruitment video	82.3	4.5
Accessible Participant Information Sheet (with visuals)	84.3	3.9
Accessible Participant Information Sheet (no visuals)	77.1	5.2
Standard Participant Information Sheet	51	10.5
Informed Consent Document	91.4	3.2
Accessible Debrief Letter	92.8	2.6
Interview Schedule ver. 3	94.1	2.6
Accessible summary of findings	86.1	4.4

Appendix 2.7: Supporting quotes for each interpretative theme presented

Theme 1, *“It’s good for me”* (Helen, line 69)

Sub-theme *“It helps you knowing you’ve been “kept healthy”* (David, line 181)

This sub-theme illustrates how participants were aware of their greater susceptibility to poorer physical health, and how the meaning of being *“kept healthy”* (David, line 181) differed between participants:

When asked what they thought was good about AHCs Louise said *“it’s just having the reassurance that there’s nothing going on”* (Louise, line 152-153)

Similarly, Helen said *“it’s good because I like to know what’s going on, and what’s wrong”* (Helen, line 169).

Carla: “...to make sure someone's healthy...Because people with learning disabilities are more likely to die quicker... They've got more health problems.”

Carer: “Can they not notice when they've got a health problem?”

Carla: “No. Someone with a learning disability wouldn't even know...if they had cancer.” (line 488-496)

“...people with a learning disability, they will die much younger than normal people... It's not fair, really...” (Jude, line 158-163)

“...if you stop annual health checks... it's not very nice because...eventually you may get something...you may have to emergency phone call to the hospital or what not.” (Ivaan, line 253-257)

“...I think the annual health check is good. Because it tells you what’s wrong with your body. And it lets the people in charge... know what’s wrong and what they can do.” (David, line 525-527)

Some participants also expressed anxiety that due to the COVID-19 pandemic, the normal physical checks had not been performed during their most recent AHC:

“I was a bit worried...because of lockdown I only had a bit done, and I have to have blood tests for my thyroid, and my kidneys cause of the tablets I'm on” (Rose, line 51-52).

I didn't get weighed or nothing, I only had a little bit done. And she didn't take my high blood pressure... Wasn't very good...I don't know if they could have done a bit more...” (Rose, line 66-105)

“...I suppose not as, not as thorough probably...Because it was over the phone and you weren't seeing anyone.” (Louise, line 175-179)

“...I'd rather be there in person so they can do...the proper tests...” (Anna, line 476-477)

“...it wasn't a full one... a little bit upset, but I understand why they not doing the full one at the moment.” (Jude, line 870-873)

The AHCs were also viewed as an important opportunity for participants and their doctors to monitor existing health conditions:

In relation to her asthma, Anna told the interviewer *“I could be having more attacks...and they're not checking my peak flow. And how do they know if my asthma is getting worse or better?”* (line 535-536).

For other participants the AHC seemed to be less about avoiding worsening health and more an opportunity to receive support to stay healthy:

“I think it's important to be reminded of good habits actually” (Mihran, line 140-141).

“It's where you go in to speak to your doctor about your daily stuff and they weigh you and ask how you've been lately and what I can do to improve myself” (Scott, line 24-25).

Sub-theme “*I have someone with me to help me*” (Anna, line 639)

This second sub-theme illustrates how participants also identified a need for extra support to access services meant to help them stay healthy:

When asked what made the difference between a good and a bad AHC several participants talked about how their appointment was made:

Rose explained that she received a letter asking her to make an appointment. Though her GP surgery required her to make an appointment over the phone, this was not easy for her to do: “...compared to what it used to be, just can't get appointments or when you want one. "Oh, you've gotta wait 3 weeks" when I had bad asthma, I said I'll be better by then I said! It's ridiculous! 3 weeks to wait for an appointment!” (Rose, line 339-341)

Interviewer: “It sounds like you would prefer to walk up to the surgery and do it in person?”

Rose: “Yeah, if I can yeah.”

Interviewer: “Is that easier than calling and waiting on the phone and maybe not getting through?”

Rose: “Yeah, because, aww (grits teeth and shakes head while letting out a sigh) frustrating, that phone, aww dear...Dear me, it's a nightmare.” (Rose, line 362-370)

Interviewer: “... what's it like to be invited to your annual health check in that way? That they send you a letter and then you have to call?”

Scott: “I'd rather them get in touch with me and say it's due, and then organise a date with me like that...because I can't remember my dates. I don't remember very well. I have to write everything down...but that's me autism. That's not my fault. My mind strays from other things you see and I can't help that.” (Scott, line 232-247)

Carla: “it's hard because...every time you make appointments you have to ring up really early otherwise all appointments are gone.”

Carer: “Usually before you wake up.”

Carla: "Yeah. And they have online bookings, and they're normally all gone." (Carla, line 381-384)

"And another problem...with phoning the doctors, they tell you that you have to phone at 8 o'clock in the morning. I'm not up at that time in the morning. I get woken up between 9 and half 9 for my medication. And even then I'm in an out, and normally after my medications I fall back asleep. I'm so fatigued. Normally I sleep in the morning. And that's another stressful thing, that they don't understand that I can't actually ring them in the morning." (Anna, line 357-362)

Interviewer: "What's that like for you to make the appointment?"

Rose: "Okay, sometimes it can be a bit, to get past the reception, they can be a bit funny sometimes.

Interviewer: And when you say funny, what do you mean?"

Rose: "Oh, "you can't make one"... "you've got to ring up at half past eight in the morning" and stuff like that for appointments and stuff. And then you ring up, it's all engaged! Get fed up I do!" (she sighs) (Rose, line 320-326)

Interviewer: "What's the difference between getting a letter in easy read and not?"

Anna: "... having a lot of words on one page...goes over my head... I just don't, especially big words like, words I won't probably...understand... A lot of jargon... and... just a lot of writing, it needs to be in pictures as well."

Interviewer: "How does that make you feel? Or what does that make you think about your doctors if they send that type of letter?"

Anna: "That they should know by now that, especially in the type of place like this where we've all got a learning disability... everybody who lives here has a learning disability....And the doctors surgery should know that by now because we've lived here for five years."

Interviewer: "...what's the feeling that's showing up there now? For you when you're telling me that... what's the feeling that goes with "they should know by now!"

Anna: "... just the same, frustrating really ...like "how long have you known us?" You know. They have actually posted me a letter ... about the flu jab. And that was in easy read."

Interviewer: And what was that like to get that letter?

Anna: I was thinking “well why, in fact, if this is in easy read, why can’t the other letters be in easy read?” (Anna, line 245-278)

Difficulties could also result from the surgery environment and the additional demands it could make on participant’s senses and attention:

David: you just sit there, waiting, wondering when is it going to be your turn... when someone comes out the nurse shouts your name. And they have it on the... TV, your name...But you’ve got to keep watching this and you wonder.

Interviewer: Is that part of the nervous too? Where you’re...making sure you don’t miss it (being called for the appointment)?

David: Yeah, that’s it. Cause you’ve got to keep your eye on that. (line 392-405)

Even when participants felt able to make an appointment independently there were additional factors to consider:

“...sometimes they give you an appointment on the letter and then you look at it and think “Oh God, I’ve got to try and work round that now.” (Louise, line 346-348).

“Sometimes it’s hard because it (the appointment) might clash with work or something. So then you’ve got to work out whether you can have...the time off work to do it...And then also you got to try and fit it in with your support time as well.” (Louise, line 400-404)

Managing the demands of communication was another area where problems could arise:

it was very stressful trying to get the appointment in the first place, because, they sent me a letter, which wasn’t in easy read...They kept saying...there’s this one doctor who I haven’t really met is doing all the annual health checks.” (Anna, line 123-127).

“It also helps having someone there in case I don’t know all the answers, or they might not know all the answers either, but, um, if someone came with me who had known me for a long time or had got to know me really well they may know the answers when I may have forgotten. Or they could prompt me, like if I told them I

wanted to mention something, they can prompt me to remind me.” (Anna, line 431-437)

“...they may talk all jargon and don't make any plumbing sense!” (Ivaan, line 419)

“...the feeling is trying to...grasp as much...words or sentences into my thought. And eventually I know exactly what they're talking about...It's ...like...the current of the communication...trying to be patient and ...get that right sentence going...otherwise ...if I just joined the conversation with...that's going to be a whole disaster.” (Ivaan, line 461-476)

In addition to these practical challenges simply being in the GP surgery, with its connections to illness and injury, could be a source of difficulty:

Scott: “It's just the fact that I'm in the doctor's ... it's the whole doctor's idea. What scares me or I don't like.”

Interviewer: “Can you tell me a bit more about the doctor's idea?”

Scott: “... just being in a place where potentially someone could be unwell or someone else could be unwell, and you don't know what's going off around you and you just want to get it over and done with.” (Scott, line 354-359)

Anna shared a similar perspective, saying that *“I always worry something's going to go wrong...because I've got a low immune system, I can catch anything, and you know, you just don't know why other people are at the doctors”* (line 658-665)

Theme 2, “*That doctor does his job, but they treat you as a person*” (David, line 558)

Sub-theme “*The people what do it, they care*” (David, line 185)

This sub-theme illustrates how what appeared to matter most was being treated respectfully as an individual.

What seemed to be shared across participants examples was a recognition of them as people with individual human needs, and a willingness from primary care staff to meet those needs:

“Oh, I like em (health checks) in a way...It sort of shows you, and makes you think, that the people what do it, they care.” (David, line 185-186)

“...they appreciate me as a person, not as a person with a learning disability.” (Jude, line 731). “They treat you...the same as anybody else.” (Jude, line 733)

“...a good health check...might be not really rushed, and...explain as clearly as possible to me.” (Mihran, line 282-283)

The presence of humour, being able to have “*a bit of fun*” with primary care staff, seemed to be important to some participants:

David: “I call em Dracula’s daughter cause they’ve got a needle (laughing). I call em that (laughing) but they know I don’t mean it, they know it’s a bit of fun.”

Interviewer: “And do they join in with you?”

David: “Oh aye, yeah. There’s one nurse... she was taking some blood out of me arm. I said “how many do you want” and she went “I want four. Two for me and two for me dad” (laughing).” (line 431-437)

Many participants identified helpful ways primary care staff had behaved towards them:

Interviewer: “Do your doctors always get it right?”

Jude: “Not always. They get some things wrong, but not all the time.”

Interviewer: “...when they do sometimes get something wrong, what happens next?”

Jude: “I would say to them you, yeah, you got that wrong.”

Interviewer: “And how do they respond?”

Jude: “Oh, sorry Jude”, you know. “Oh, I know it should be that”.

Interviewer: “...and then do they try it differently?”

Jude: “Um, sometimes they try it differently, like no jargon at all.” (Jude, line 925-938)

“I thought he was absolutely amazing, because he looked at me, even though my Mum was with me. He looked at me and asked me the questions even though I couldn’t always answer them, but he looked at me rather than Mum because I’m the patient. And I’m really impressed with that.” (Anna, line 70-73)

“if the doctor is talking to me, and the nurse is talking to my Mum and me...that’s actually reassuring” (Mihran, line 162-163)

Sub-theme “*You want the doctor to actually know the person*” (Carla, line 262)

This second sub-theme communicates how knowing and being known by primary care staff gave participants confidence that they would be treated respectfully and that their AHC would be done properly.

Many examples of how participants were made to feel respected also seemed to involve familiar and preferred primary care staff:

“most of the time it's been pretty good, but that's probably because of the doctor I had before I moved here, I'd known him since I was 14 (years old)” (Scott, line 127-129).

“I think if you can see any doctor it’s difficult to, like, get to know them right, but if you stay with one doctor you get to know them really well and then you feel comfortable talking to them.” (Anna, line 21-23).

“And this is another reason why I like seeing this doctor because she talks to me...if there is something that I’m stuck with then that’s when whoever I’m with is there to help.” (Anna, line 60-61).

“I especially like one receptionist who has gone out of her way to help me when I was really upset one time....I was waiting and she saw me upset and she brought me to another room and we had a chat. And that was really nice that she did that. And since then she’s like “Hi!” you know, always like, you know, smiley, chatty and always ready to help me, you know.” (Anna, line 940-944)

Theme 3, “*I think doctors should be a bit more understanding with disabilities*” (Scott, line 157)

Sub-theme “*Haven’t they looked at my records?*” (Rose, line 287)

This sub-theme summarises the frustration, annoyance, and sometimes disbelief experienced by participants when such a lack of understanding occurred.

While familiarity seemed to provide reassurance, a lack of consistency in who participants saw seemed to be connected in their mind with a lack of knowledge regarding their health history:

“I write it on the envelope...the name of the doctor...that gives me a clue of what doctor I’m going to meet, but it’s still strange different doctor, but the doctor's name it’s a very important thing actually.” (Ivaan, line 331-351)

Teri: “Well one time we would have seen the doctor, and another time you just see the nurse doing the health check.”

Interviewer: “Does it tend to be the same person or a different person every time?”

Teri: “Sometimes a different person.”

Interviewer: “And what's that like for you? That it could be a different person each time?”

Teri: “Yeah, it can be very sort of frustrating.” (Teri, line 511-520)

Interviewer: “...would you know what will happen in your health check?

Scott: “They just talk to me about my health, my weight... what problems I may have or might not have.”

Interviewer: “...knowing about that going in, do you feel any different other than worried?”

Scott: “Just worried... I don't know what they're going to say, or going to do.”

Interviewer: “Even though you've had annual health checks before, every time, you're not sure?”

Scott: “Yeah. Because everyone's different.”

Interviewer: “...you said before that when you first started getting health checks it was always...the GP you'd had for a long time.”

Scott: “But the next time I have one, it will be a completely new Doctor.”
(Scott, line 383-393)

Experiencing a lack of respect from primary care staff was often voiced in terms of poor awareness of their individual health needs and that the AHC was not being performed properly:

“...I asked for a female doctor...They said that they haven't got one. But they have.”
(Carla, line 221-223)

“...it was another nurse I've never seen before that time. And she didn't introduce herself or nothing. And the (self-advocacy group)...wrote a letter ... about it to complain ... because I wasn't happy at all.” (Rose, line 121-123)

“I know when the person's not engaging with me. They're always tapping on the computer” (Teri, line 117-118)

Interviewer: “... how does that make you feel when they're looking at the computer and not at you?”

Anna: “...it makes me feel like they're not listening to me as much.”

Interviewer: “So they're not listening to you and they're not paying attention?”

Anna: “Yeah.”

Interviewer: “And...how does that make you feel about the appointment, about them, and about you?”

Anna: Um, frustrated...because I want to be able to get my point or whatever across, and... from past experiences they...don't always wait until I finish what I want to say and they guess...what I'm gonna finish saying” (Anna, line 206-219)

Interviewer: “And when that happens (when they speak to your support worker and not you), what do you think of the doctor? Or what do you think the doctor or nurse think of you?”

Teri: “Well I just think they need to go on training. Because it's not, I think it's sometimes the way they are actually thinking in their head. Somebody with a disability, oh don't worry, they're not worried, you know. I don't know, it's you know, a very tricky one.” (Teri, line 337-341)

Most participants gave examples of primary care staff behaviour that seemed to demonstrate a lack of understanding regarding their diagnoses and associated needs:

Scott: "...I remember at the last health check. It's a bit ago, I remember him trying to be a bit, it was more like they were in a hurry because they had other appointments that day. if that makes sense, but it wasn't their fault."

Interviewer: "And what was that like to feel like they were in a hurry?"

Scott: "A bit annoying."

Interviewer: "What kind of things were they doing that it felt like they were in a hurry?"

Scott: "It was just not explaining it slowly enough....And were a bit quick with their explanations" (line 172-182)

"It depends how quick, I know when the person's not engaging with me. They're always tapping on the computer or whatever." (Teri, line 117-118)

Participants in this study had also encountered difficulty due to a lack of awareness concerning their visual or hearing impairments:

"...a good one is...taking time, not rushing you...not look at the computer screen when they're talking because I find it hard, um, talking, hearing what they're saying if they're not looking at me. Because I've got 50% hearing in my right ear. And if there's background noise or they're not looking at me that's when I struggle." (Anna, line 197-200)

Teri: Cause they've gone back to the old school. It feels like they're going back to the old school where you have to try and work your way around (laughing), you know....where they're just using their own voices and not the screens anymore. See when I was in my other (doctors surgery) they had screens and they spoke. And they gave me an idea. And they've got the computer where you can (check in for your appointment) but that...doesn't even speak to you when you tap. I think they should have a speaking system."

Interviewer: "Do you find it difficult to see things if they're, if they're not in large print?"

Teri: "Yes. Cause I'm registered partially sighted."

Interviewer: "So the screens made it easier for you to be able to see where you're meant to go and when?"

Teri: "Yes. And it would come up big! And sometimes you'd see a picture of a nurse on the screen. Room 1. And you'd know where you were going! And if they was

sending their paperwork out they would send it with a picture of the doctor you're seeing!"

Interviewer: "And how would that make you feel if they did that in the surgery you go to now?"

Teri: "It'd make you feel a lot easier." (line 425-442)

Other participants described how the actions of some primary care staff felt like attempts to dictate how they should live their lives:

During one of her previous AHCs, shortly after she had fallen at home, Rose shared what had been said to her: *"the one doctor said I shouldn't be living on my own! And I thought that, that wasn't very nice to say"* (line 174-175).

Interviewer: "Okay... then when the smoking question comes up"

Jude: (she smiles, then quickly shakes her head) "Un uh!"

Interviewer: "Un uh! ...I'm trying to get down to ... a feeling or a thought that might come up..."

Jude: There's no feeling or thought behind it, it's just, sometimes...they know I'm ... lying a little bit about this one" (laughing)

Interviewer: And do they ever... wag the finger?"

Jude: "Sometimes (laughing), sometimes yes (laughing) "You need to quit, you need to quit".

Interviewer: "And what's that like?"

Jude: "It's annoying...I said "I know, I know I need to quit. But if I do quit I'll put on weight" I say to them." (Jude, line 443-455)

Interviewer: "Is that a conversation you ever get to have with your doctor in the annual health check?"

Jude: Not really no... they can see on the screen, about my diabetes and all...I don't bring it up at all to em. I know I should, but no, they don't ask."

Interviewer: "Would you tell me...why you don't bring that... 'stuckness' up?"

Jude: Because... I think they already got too much on their plate with other people's problems and I don't want to put my problems on to them."

Interviewer: "...do you think that they would listen if you did tell them?"

Jude: "Yeah, in a way...I think they would listen, and they will think about it and then they come back with another answer sort of thing." (line 482-499)

Interviewer: "Do they ask you about things like your diet?"

Scott: "Sometimes, not all the time."

Interviewer: "Not all the time. So you told me a bit about when they... weigh you...and that you don't like that is that right?"

Scott: "Well I hate it, the idea of knowing what my weight is, it's a bit cringy."

Interviewer: "...is cringy the same as embarrassing?"

Scott: "Yeah."

Interviewer: "... What kind of things did they say?"

Scott: "Normally that I need to lose a bit of weight, you need to diet a little. I'm not very good at that."

Interviewer: "And that part of the check feels a bit cringy?"

Scott: "Yeah." (Scott, line 528-542)

Sub-theme "*You've got to have something to back you up, to help you*" (David, line 321)

This sub-theme articulates how, in addition to the need for help to access health services, people with an intellectual disability also felt the need for support to ensure that they and their goals were treated with respect by primary care staff.

For each participant who described needing and benefiting from such back up, it ultimately seemed to be about improving the accessibility of their AHC appointment. Importantly, this was about reducing both the cognitive and emotional demands of the process:

"That extra, uh, um, helping hand is...really an advantage for me (laughing) because otherwise, uh, what I would do if my Mum, or if one of my parents are not there, what I will do, I'm not going to get out of the room and go....I do have a back up plan. Uh, the nurse will be there. I will ask the nurse the same thing that I'm doing with my Mum. And eventually the nurse will tell me what, what it is (that the doctor is asking). And I would tell the doctor what to do." (Ivaan, line 727-732)

David: "You've got to have a system. Cause if you don't have a system you're gonna be lost. You've got to have something to back you up, to help you in a way."

Interviewer: "And is that how it feels for you, the way that things work, that you've got your brother there to back you up and help you?"

David: "Yeah. I know if, I can phone me brother up any time I want and say to him, tell him I need him and I know he'd do something straight away. You've got to have a back up somewhere, whoever it is." (David, line 320-326)

"I can't read, and I can't write. And I'm disabled as you know...So all information what comes to me I let him, me brother take and have a look and sort things out. Anything important goes to me brother and he will sort it out." (David, line 254-257)

Interviewer: "What help, if any, do you need to go to your annual health checks?"

Scott: "Well, originally my foster Mum used to go with me to my annual health check...I normally...have her come with me to explain everything what I couldn't possibly explain." (Scott, line 64-68)

Interviewer: "So your support worker will go with you into the health check?"

Louise: "Yeah."

Interviewer: "And does that help make it easier or harder to have a health check?"

Louise: "Probably easier."

Interviewer: "What is it that they do that makes it easier?"

Louise: "Don't know, just that they're in the room in case I need their help."

Interviewer: "What kind of help might you need?"

Louise: "Explaining stuff or whatever."

Interviewer: "So is that...explaining stuff that the nurse is saying to you?"

Louise: "Yeah."

Interviewer: "And is it explaining stuff that you want to tell the nurse?"

Louise: "Yeah. Both, both ways." (Louise, line 615-626)

Interviewer: "... whenever they're using lots of jargon or they're saying things that don't make sense to you, what does your Mum do then?

Ivaan: "... my Mum would be so much like... Eventually put,... make sense words into it. Like proper."

Interviewer: "Your Mum would help make sense of it?"

Ivaan: "Yeah, to get proper words into it. And eventually they get eventually get the, get the, get the words out of my Mum, uh, proper words. And eventually it comes back to me and I, I just answer it so."

Interviewer: "... so your Mum helps what they say make sense...?"

Ivaan: "Yeah, making sense." (Ivaan, line 427-438)

"Because sometimes I know they've got to use some jargon, 'jargonese' ... to explain things. That's so difficult for me to understand so sometimes I ask...to bring my sister along with me to explain it more better..." (Jude, line 940-942)

However, having 'back up' did not guarantee a satisfying experience. At times it could result in the person with an intellectual disability feeling even more excluded and disempowered:

"...the bad health check is talking to the carers, not talking to the person with the learning disability." (Jude, line 656-657)

Mihran: "Upsetting and annoying actually, because...sometimes she can be really irritating, but sometimes she can be loving actually. My Mum I mean."

Interviewer: "But sometimes it can be irritating when someone speaks for you?"

Mihran: "Yeah." (line 105-109)

"Sometimes it becomes annoying because she, whenever she discovers a health problem at home she keeps on reminding me and it becomes more annoying..." (Mihran, line 444-446)

Appendix 2.8: Accessible summary letter provided to participants



Dear (participant),

A few months ago you helped me learn what it's like for you to have an Annual Health Check.



I spoke to you and other people with a learning disability. This letter tells you what I learnt from everyone. I want to know what you think of what I learnt.



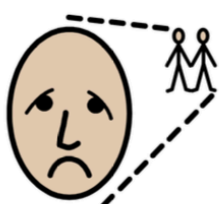
I learnt that Annual Health Checks are better when it feels like the doctor, nurse, or other staff care. People feel cared for when:



- they know the person doing their health check.
- they can smile with the person doing their health check.
- they feel listened to.
- the health check is about their body and their personal health.



I learnt that Annual Health Checks are worse if it feels like the doctor, nurse, or other staff don't care. People don't feel cared for when:



- they can't talk about what was important to them.
- the doctor, nurse or other staff don't look at or speak to them.
- the doctor, nurse or other staff don't change how they do things to make it easier for people with a learning disability.



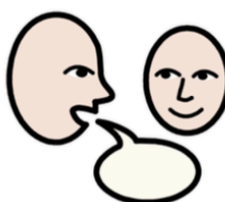
I learnt that even when Annual Health Checks are good the way things are done can make it harder. Annual Health Checks are harder if:



- you are asked to do things that are hard for anyone with a learning disability.
- the doctor, nurse or staff uses jargon and words you don't know.



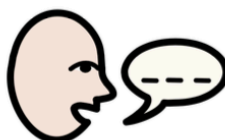
Having help from someone you trust makes Annual Health Checks easier when they:



- help you understand the doctor, nurse and staff.
- help the doctor, nurse and staff understand you.
- help you if you feel anxious or upset.



If you agree with what I've learnt you don't have to do anything.



If you do agree and you want to tell me why, you can.



If you don't agree and you want to tell me why, I would like you to contact me.



You can contact me by phone call, text or WhatsApp. My number is
07915 944 329.



You can send me an e-mail. My e-mail address is
bodelj@uni.coventry.ac.uk



Thank you for helping me with my study.

Yours sincerely,

Andrew Bodel, Trainee Psychologist

Appendix 2.9: Ethical approval documents



Certificate of Ethical Approval

Applicant:

James Bodel

Project Title:

Experiences of the Annual Health Check Process amongst People with a Learning Disability

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

01 July 2020

Project Reference Number:

P95143



Medium to High Risk Research Ethics Approval

Project Title

Experiences of the Annual Health Check Process amongst People with a Learning Disability

Record of Approval

Principal Investigator

I request an ethics peer review and confirm that I have answered all relevant questions in this checklist honestly.	X
I confirm that I will carry out the project in the ways described in this checklist. I will immediately suspend research and request new ethical approval if the project subsequently changes the information I have given in this checklist.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the Code of Research Ethics issued by the relevant national learned society.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the University's Research Ethics, Governance and Integrity Framework.	X

Name: James Bodel.....

Date: 04/10/2019.....

Student's Supervisor (if applicable)

I have read this checklist and confirm that it covers all the ethical issues raised by this project fully and frankly. I also confirm that these issues have been discussed with the student and will continue to be reviewed in the course of supervision.

Name: Anthony Colombo.....

Date: 01/04/2020.....

Reviewer (if applicable)

Date of approval by anonymous reviewer: 01/07/2020

Medium to High Risk Research Ethics Approval Checklist

Project Information

Project Ref	P95143
Full name	James Bodel
Faculty	Faculty of Health and Life Sciences
Department	School of Psychological, Social and Behavioural Sciences
Supervisor	Anthony Colombo
Module Code	D62PY
EFAAF Number	
Project title	Experiences of the Annual Health Check Process amongst People with a Learning Disability
Date(s)	01/04/2020 - 31/10/2022
Created	04/10/2019 13:54

Project Summary

This study aims to explore the lived experience of receiving an Annual Health Check (AHC) from the perspective of people with a learning disability (LD).

AHCs reduce the health inequalities experienced by this group and increasing their availability and uptake is a national priority. However, rates of attendance remain below the 2020 75% target set by NHS England and barriers are under researched. Understanding the experience from the perspective of recipients may help improve engagement between people with a learning disability and professionals providing AHCs.

The study will employ an Interpretative Phenomenological Analysis (IPA) design, using videoconference or telephone interviews with 6 to 10 participants in order to explore their experiences of the AHC process – from the initial invitation, to attending the appointment and the post appointment stage.

Names of Co-Investigators and their organisational affiliation (place of study/employer)	
Is the project self-funded?	YES
Who is funding the project?	NHS England
Has the funding been confirmed?	YES
Are you required to use a Professional Code of Ethical Practice appropriate to	YES

your discipline?	
Have you read the Code?	YES

Project Details

What is the purpose of the project?	<p>This study aims to explore the lived experience of receiving an AHC from the perspective of people with a LD.</p> <p>There are approximately 1.2 million people with a LD living in England who have a significantly reduced average life expectancy compared to the general population due, in part, to unequal access to health care.</p> <p>In 2008 NHS England launched the Annual Health Check (AHC) scheme to encourage preventative health screening for people with LD via their GP. In 2018 just over half (55%) of all registered LD patients in England received an AHC (see attached research proposal for details).</p> <p>It remains unclear whether people with a LD actively choose not to attend AHCs, and if so the reasons for that choice. Previous research suggests that anxieties, fears and experiences of exclusion and discrimination in health care settings may affect the number of successful AHCs. More research is needed to understand the factors that may impact the decision to accept or decline an AHC invitation.</p>
What are the planned or desired outcomes?	<p>To answer the question “what are the lived experiences of people with a LD who go through the AHC process?”</p> <p>The study will explore participants experiences at several stages in the AHC process – being invited to attend an AHC appointment; attending the AHC appointment; and post AHC interactions and support.</p> <p>The study hopes to gain an understanding of these experiences in terms of:</p> <ol style="list-style-type: none"> 1) the range of meanings participants

	<p>voice in terms of their thoughts, emotions and beliefs</p> <p>2) the role that others (e.g. carers and health professionals) play in shaping these thoughts, emotions and beliefs</p> <p>3) the potential facilitators and barriers to attending the AHC; and</p> <p>4) ways forward in terms of improving policy and practice towards increased uptake of the AHCs</p>
Explain your research design	<p>The study will follow an IPA methodology. Recruitment of participants will be via private and charitable organisations that provide support to people with a LD. Purposive sampling will be used to identify potential participants from service users in contact with these organisations.</p> <p>Potential participants will be invited to participate in the study by post or e-mail sent from these organisations.</p> <p>Data will be collected using semi-structured videoconference or telephone interviews which will be recorded.</p> <p>Recorded interviews will be transcribed verbatim. Interview transcripts will be analysed according to the principals of IPA. A final draft of the analysis will be shown to consenting study participants to confirm the accuracy of the written interpretations of their experience.</p>
Outline the principal methods you will use	<p>Recruitment:</p> <p>1) Private and charitable organisations who support people with a LD will be asked to facilitate the recruitment of participants to the study. Participating organisations will identify service users who meet the inclusion and exclusion criteria of the study (attachment</p>

	<p>7).</p> <p>2) An accessible letter explaining the purpose of the study and an invitation to take part will be posted or e-mailed to potential participants.</p> <p>3) Interested potential participants will be asked to contact the researcher via phone for an appointment to review the Participant Information Sheet (PIS, attachment 2) and consent document (attachment 3). This appointment can be with the researcher via videoconference or with a trusted other.</p> <p>4) During the appointment the potential participant and the researcher or a trusted other will review the PIS and the consent document. A copy of both will be e-mailed or posted to the potential participant depending on their preference.</p> <p>5) Where the potential participant demonstrates capacity to consent, understanding of the PIS and wishes to participate a video or telephone interview with the researcher will be scheduled. Where a video interview is scheduled, and the participant requires or wishes to have the support of a trusted other, informed consent from the trusted other to be recorded will be agreed and documented on the consent form prior to interview. Consent will be documented by signing the consent form and returning either a picture, scanned copy or the signed document to the researcher.</p> <p>Data collection:</p> <p>1) Consent will be reconfirmed prior to beginning the interview.</p> <p>2) Interview will take place via videoconference or telephone. Video interviews will be conducted using Microsoft Teams or Skype for Business</p>
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	<p>which are secure and encrypted and only require the potential participant to have access to the internet, a compatible device and the necessary support to use the device.</p> <p>3) Interviews will be supported by an interview schedule (attachment 4) that will provide additional structure to aid data collection should participants require these adaptations due to their LD. Interviews will be recorded and last for approximately 1 hour, with time after for participant debriefing with reference to a debrief letter (attachment 5) that will be e-mailed or posted to them prior to the interview.</p> <p>Data analysis:</p> <p>1) Recorded interviews will be transcribed verbatim. Names will be changed and references to other people, specific services or locations altered to preserve anonymity while retaining the meaning of the containing statement. Once transcribed the recordings will be deleted.</p> <p>2) A password protected digital document will be made to act as a key to reverse the anonymisation should a participant decide to withdraw and request that their information is removed. The key to reverse the anonymisation will be stored separately from interview transcripts.</p> <p>3) All documents will be password protected and stored securely using the Microsoft One Drive cloud storage linked to the researchers Coventry University e-mail account. Different passwords will be used to protect the transcript documents and the document containing the reverse anonymisation key.</p> <p>4) Interview transcripts will be</p>
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	<p>analysed according to the principals of IPA. Analysis will be performed using the digital copy of each transcript. No physical copies of transcripts will be produced. The transcripts will only be saved on, and accessed from, the secure One Drive cloud storage account.</p> <p>5) A final draft of the analysis will be presented to study participants (who have given their consent at both the initial consent stage and debrief stage to participate in this later stage of the research) who will be asked to critique the interpretations of their experiences.</p>
Are you proposing to use an external research instrument, validated scale or follow a published research method?	NO
If yes, please give details of what you are using	
Will your research involve consulting individuals who support, or literature, websites or similar material which advocates, any of the following: terrorism, armed struggles, or political, religious or other forms of activism considered illegal under UK law?	NO
Are you dealing with Secondary Data? (e.g. sourcing info from websites, historical documents)	NO
Are you dealing with Primary Data involving people? (e.g. interviews, questionnaires, observations)	YES
Are you dealing with personal or sensitive data?	YES
Will the Personal or Sensitive data be shared with a third party?	NO
Will the Personal or Sensitive data be shared outside of the European Economic Area ("EEA")?	NO
Is the project solely desk based? (e.g. involving no laboratory, workshop or off-campus work or other activities which pose significant risks to researchers or participants)	NO
Are there any other ethical issues or risks of harm raised by the study that have not been covered by previous questions?	YES
If yes, please give further details	<p>Inclusion - People with a LD will be involved at four principal stages - in the design of the study; the design of recruitment and data collection materials; the initial analysis; and in review of the final analysis.</p> <p>Right to withdraw - Participants will be reminded at each stage of their right to withdraw any time before March 2021. However, it should be noted that after 2</p>

	<p>weeks the interview will have been transcribed and the recording deleted.</p> <p>Minimising risk of harm & burden to participants - Interviews that focus on previous healthcare experiences may trigger recollection of unpleasant experiences. Participants will be made aware of the studies distress protocol (attachment 7). Where a participant experiences distress the interview will be stopped. Participants will be asked if they would like to take a break. Participants will be offered the choice of continuing the interview after a short break, stopping and rescheduling the interview for another day or withdrawing completely from the study.</p>
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DBS (Disclosure & Barring Service) formerly CRB (Criminal Records Bureau)

Question		Yes	No
1	Does the study require DBS (Disclosure & Barring Service) checks?	X	
	<p>If YES, please give details of the serial number, date obtained and expiry date</p> <p>The main researchers DBS details are as follows:</p> <p>Certificate no. 001627502051</p> <p>Issue date: 23/08/2018</p> <p>Expiry date: 22/08/2020</p> <p>The main researcher has subscribed to the yearly auto-renewal service for the DBS.</p>		
2	If NO, does the study involve direct contact by any member of the research team:		
	a) with children or young people under 18 years of age?		
	b) with adults who have learning difficulties, brain injury, dementia, degenerative neurological disorders?		
	c) with adults who are frail or physically disabled?		
	d) with adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?		
	e) with adults who are in prison, remanded on bail or in custody?		
	If you have answered YES to any of the questions above please explain the nature of that contact and what you will be doing		

External Ethical Review

Question		Yes	No
1	Will this study be submitted for ethical review to an external organisation? (e.g. Another University, Social Care, National Health Service, Ministry of Defence, Police Service and Probation Office) If YES, name of external organisation		X
2	Will this study be reviewed using the IRAS system?		X
3	Has this study previously been reviewed by an external organisation?		X

Confidentiality, security and retention of research data

Question		Yes	No
1	Are there any reasons why you cannot guarantee the full security and confidentiality of any personal or confidential data collected for the study?		X
	If YES, please give an explanation		
2	Is there a significant possibility that any of your participants, and associated persons, could be directly or indirectly identified in the outputs or findings from this study?		X
	If YES, please explain further why this is the case		
3	Is there a significant possibility that a specific organisation or agency or participants could have confidential information identified, as a result of the way you write up the results of the study?		X
	If YES, please explain further why this is the case		
4	Will any members of the research team retain any personal or confidential data at the end of the project, other than in fully anonymised form?		X
	If YES, please explain further why this is the case		
5	Will you or any member of the team intend to make use of any confidential information, knowledge, trade secrets obtained for any other purpose than the research project?		X
	If YES, please explain further why this is the case		
6	Will you be responsible for destroying the data after study completion?		X
	If NO, please explain how data will be destroyed, when it will be destroyed and by whom	<p>No paper documents will be used to record or analyse participant data during this project.</p> <p>Return of consent documents will be via a scanned copy sent by e-mail only. Participation will require access to the internet and an e-mail account.</p> <p>Following the completion of the project all electronic data will be transferred to Dr. Anthony Colombo, Academic Supervisor, for storage on the Doctorate in Clinical Psychology Microsoft OneDrive account.</p> <p>Coventry University will retain project documentation such as consent forms</p>	

		<p>following the submission of this thesis project.</p> <p>All information will be destroyed by Coventry University after 5 years from the end of the project, in line with their policies and procedures.</p>
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Participant Information and Informed Consent

Question		Yes	No
1	Will all the participants be fully informed BEFORE the project begins why the study is being conducted and what their participation will involve?	X	
	If NO, please explain why		
2	Will every participant be asked to give written consent to participating in the study, before it begins?	X	
	If NO, please explain how you will get consent from your participants. If not written consent, explain how you will record consent		
3	Will all participants be fully informed about what data will be collected, and what will be done with this data during and after the study?	X	
	If NO, please specify		
4	Will there be audio, video or photographic recording of participants?	X	
	Will explicit consent be sought for recording of participants?	X	
	If NO to explicit consent, please explain how you will gain consent for recording participants		
5	Will every participant understand that they have the right not to take part at any time, and/or withdraw themselves and their data from the study if they wish?	X	
	If NO, please explain why		
6	Will every participant understand that there will be no reasons required or repercussions if they withdraw or remove their data from the study?	X	
	If NO, please explain why		
7	Does the study involve deceiving, or covert observation of, participants?		X
	Will you debrief them at the earliest possible opportunity?		
	If NO to debrief them, please explain why this is necessary		

Risk of harm, potential harm and disclosure of harm

Question		Yes	No
1	Is there any significant risk that the study may lead to physical harm to participants or researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		
2	Is there any significant risk that the study may lead to psychological or emotional distress to participants?		X
	If YES, please explain how you will take steps to reduce or address those risks		
3	Is there any risk that the study may lead to psychological or emotional distress to researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		
4	Is there any risk that your study may lead or result in harm to the reputation of participants, researchers, or their employees, or any associated persons or organisations?		X
	If YES, please explain how you will take steps to reduce or address those risks		
5	Is there a risk that the study will lead to participants to disclose evidence of previous criminal offences, or their intention to commit criminal offences?		X
	If YES, please explain how you will take steps to reduce or address those risks		
6	Is there a risk that the study will lead participants to disclose evidence that children or vulnerable adults are being harmed, or at risk or harm?		X
	If YES, please explain how you will take steps to reduce or address those risks		
7	Is there a risk that the study will lead participants to disclose evidence of serious risk of other types of harm?		X
	If YES, please explain how you will take steps to reduce or address those risks		
8	Are you aware of the CU Disclosure protocol?	X	

Payments to participants

Question		Yes	No
1	Do you intend to offer participants cash payments or any kind of inducements, or reward for taking part in your study?		X
	If YES, please explain what kind of payment you will be offering (e.g. prize draw or store vouchers)		
2	Is there any possibility that such payments or inducements will cause participants to consent to risks that they might not otherwise find acceptable?		
3	Is there any possibility that the prospect of payment or inducements will influence the data provided by participants in any way?		
4	Will you inform participants that accepting payments or inducements does not affect their right to withdraw from the study at any time?		

Capacity to give valid consent

Question		Yes	No
1	Do you propose to recruit any participants who are:		
	a) children or young people under 18 years of age?		X
	b) adults who have learning difficulties, mental health condition, brain injury, advanced dementia, degenerative neurological disorders?	X	
	c) adults who are physically disabled?		X
	d) adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?	X	
	e) adults who are in prison, remanded on bail or in custody?		X
<p>If you answer YES to any of the questions please explain how you will overcome any challenges to gaining valid consent</p>		<p>Service users who want to participate will be asked via an accessible invitation letter to contact the researcher and opt into the study. The need to self-select as a participant provides initial evidence of capacity to provide informed consent and protection against coercion.</p> <p>The potential participant and the researcher or a trusted other will review an accessible participant information sheet (PIS) and an accessible informed consent document. This provides collateral evidence of a potential participants capacity to consent.</p> <p>Potential participants will have the opportunity to ask the researcher questions, express concerns and receive support to decide if they want to participate in the study. Informed consent will be based on a full reading of the PIS and the potential participant answering 'yes' to each question in the consent document.</p> <p>Where the researcher and/or a trusted other is satisfied that the person has understood the information in the PIS, has capacity to consent and the potential participant expresses their wish to participate both will sign the consent document.</p> <p>Consent will be reconfirmed at the</p>	

		beginning of each interview.	
2	Do you propose to recruit any participants with possible communication difficulties, including difficulties arising from limited use of knowledge of the English language?	X	
	If YES, please explain how you will overcome any challenges to gaining valid consent	<p>Potential participants will be provided with accessible information at each stage detailing what they will be asked to do, what will happen with their information, their rights and how to exercise them.</p> <p>All documents and supporting materials have been co-constructed by the researcher, an Expert Reference Group (ERG) of people with a LD and a CLDT Speech and Language Therapist (SaLT). Materials have also been assessed for readability in reference to the Flesch reading ease scale (attachment 6).</p>	
3	Do you propose to recruit any participants who may not be able to understand fully the nature of the study, research and the implications for them of participating in it or cannot provide consent themselves?		X
	If YES, please explain how you will overcome any challenges to gaining valid consent		

Recruiting Participants

Question		Yes	No
1	Do you propose to recruit any participants who are:		
	a) students or employees of Coventry University or partnering organisation(s)?		X
	If YES, please explain if there is any conflict of interest and how this will be addressed		
	b) employees/staff recruited through other businesses, voluntary or public sector organisations?		X
	If YES, please explain how permission will be gained		
c)	pupils or students recruited through educational institutions (e.g. primary schools, secondary schools, colleges)?		X
	If YES, please explain how permission will be gained		
d)	clients/volunteers/service users recruited through voluntary public services?	X	
	If YES, please explain how permission will be gained		<p>Private and charitable organisations who provide support to people with a LD will be approached and asked for support to recruit participants to the study. Organisations who agree to assist the researcher will identify service users who meet the inclusion and exclusion criteria of the study (attachment 7).</p> <p>An accessible letter explaining the purpose of the study and an invitation to take part will be posted or e-mailed to potential participants. Potential participants will be invited to self-select in order to take part in the study.</p> <p>Interested potential participants will be asked to contact the researcher via phone for an appointment to review the Participant Information Sheet (PIS, attachment 2) and consent document (attachment 3). This appointment can be with the researcher via video-conference or with a trusted other. During the appointment the potential participant and the researcher or a trusted other will review the PIS and the</p>

		consent document. Where the potential participant demonstrates capacity to consent, understanding of the PIS and wishes to participate a video or telephone interview with the researcher will be scheduled.		
e)	participants living in residential care, social care, nursing homes, re-ablement centres hospitals or hospices?	X		
	If YES, please explain how permission will be gained	Potential participants will be drawn from active service users of private and charitable organisations who provide support to people with a LD living in the community. Service users live in a variety of accommodation types that may include supported living and residential care.		
f)	recruited by virtue of their employment in the police or armed forces?			X
	If YES, please explain how permission will be gained			
g)	adults who are in prison, remanded on bail or in custody?			X
	If YES, please explain how permission will be gained			
h)	who may not be able to refuse to participate in the research?			X
	If YES, please explain how permission will be gained			

Online and Internet Research

Question		Yes	No	
1	Will any part of your study involve collecting data by means of electronic media (e.g. the Internet, e-mail, Facebook, Twitter, online forums, etc)?		X	
	If YES, please explain how you will obtain permission to collect data by this means			
2	Is there a possibility that the study will encourage children under 18 to access inappropriate websites, or correspond with people who pose risk of harm?		X	
	If YES, please explain further			
3	Will the study incur any other risks that arise specifically from the use of electronic media?		X	
	If YES, please explain further			
4	Will you be using survey collection software (e.g. BoS, Filemaker)?		X	
	If YES, please explain which software			
5	Have you taken necessary precautions for secure data management, in accordance with data protection and CU Policy?	X		
	If NO	please explain why not		
	If YES	Specify location where data will be stored	Data will be stored securely on the researchers' OneDrive account. Consent documents will be returned via a scanned copy sent by e-mail only. Consent documents will be saved to One Drive and then deleted from the researcher's inbox and deleted folder. Following completion of the project all electronic data will be transferred to the academic supervisor for storage on the Doctorate in Clinical Psychology OneDrive account.	
		Planned disposal date	31/10/2026	
		If the research is funded by an external organisation, are there any requirements for storage and disposal?		X
		If YES, please specify details		

Languages

Question		Yes	No
1	Are all or some of the consent forms, information leaflets and research instruments associated with this project likely to be used in languages other than English?		X
	If YES, please specify the language[s] to be used		
2	Have some or all of the translations been undertaken by you or a member of the research team?		
	Are these translations in lay language and likely to be clearly understood by the research participants?		
	Please describe the procedures used when undertaking research instrument translation (e.g. forward and back translation), clarifying strategies for ensuring the validity and reliability or trustworthiness of the translation		
3	Have some or all of the translations been undertaken by a third party?		
	If YES, please specify the name[s] of the persons or agencies performing the translations		
	Please describe the procedures used when undertaking research instrument translation (e.g. forward and back translation), clarifying strategies for ensuring the validity and reliability of the translation		

Laboratory/Workshops

Question		Yes	No
1	Does any part of the project involve work in a laboratory or workshop which could pose risks to you, researchers or others?		X
	<p>If YES:</p> <p>If you have risk assessments for laboratory or workshop activities you can refer to them here & upload them at the end, or explain in the text box how you will manage those risks</p>		

Research with non-human vertebrates

Question		Yes	No
1	Will any part of the project involve animal habitats or tissues or non-human vertebrates?		X
	If YES, please give details		
2	Does the project involve any procedure to the protected animal whilst it is still alive?		
3	Will any part of your project involve the study of animals in their natural habitat?		
	If YES, please give details		
4	Will the project involve the recording of behaviour of animals in a non-natural setting that is outside the control of the researcher?		
	If YES, please give details		
5	Will your field work involve any direct intervention other than recording the behaviour of the animals available for observation?		
	If YES, please give details		
6	Is the species you plan to research endangered, locally rare or part of a sensitive ecosystem protected by legislation?		
	If YES, please give details		
7	Is there any significant possibility that the welfare of the target species of those sharing the local environment/habitat will be detrimentally affected?		
	If YES, please give details		
8	Is there any significant possibility that the habitat of the animals will be damaged by the project, such that their health and survival will be endangered?		
	If YES, please give details		
9	Will project work involve intervention work in a non-natural setting in relation to invertebrate species other than <i>Octopus vulgaris</i> ?		
	If YES, please give details		

Blood Sampling / Human Tissue Analysis

Question		Yes	No
1	Does your study involve collecting or use of human tissues or fluids? (e.g. collecting urine, saliva, blood or use of cell lines, 'dead' blood)		X
	If YES, please give details		
2	If your study involves blood samples or body fluids (e.g. urine, saliva) have you clearly stated in your application that appropriate guidelines are to be followed (e.g. The British Association of Sport and Exercise Science Physiological Testing Guidelines (2007) or equivalent) and that they are in line with the level of risk?		
	If NO, please explain why not		
3	If your study involves human tissue other than blood and saliva, have you clearly stated in your application that appropriate guidelines are to be followed (e.g. The Human Tissues Act, or equivalent) and that they are in line with level of risk?		
	If NO, please explain why not		

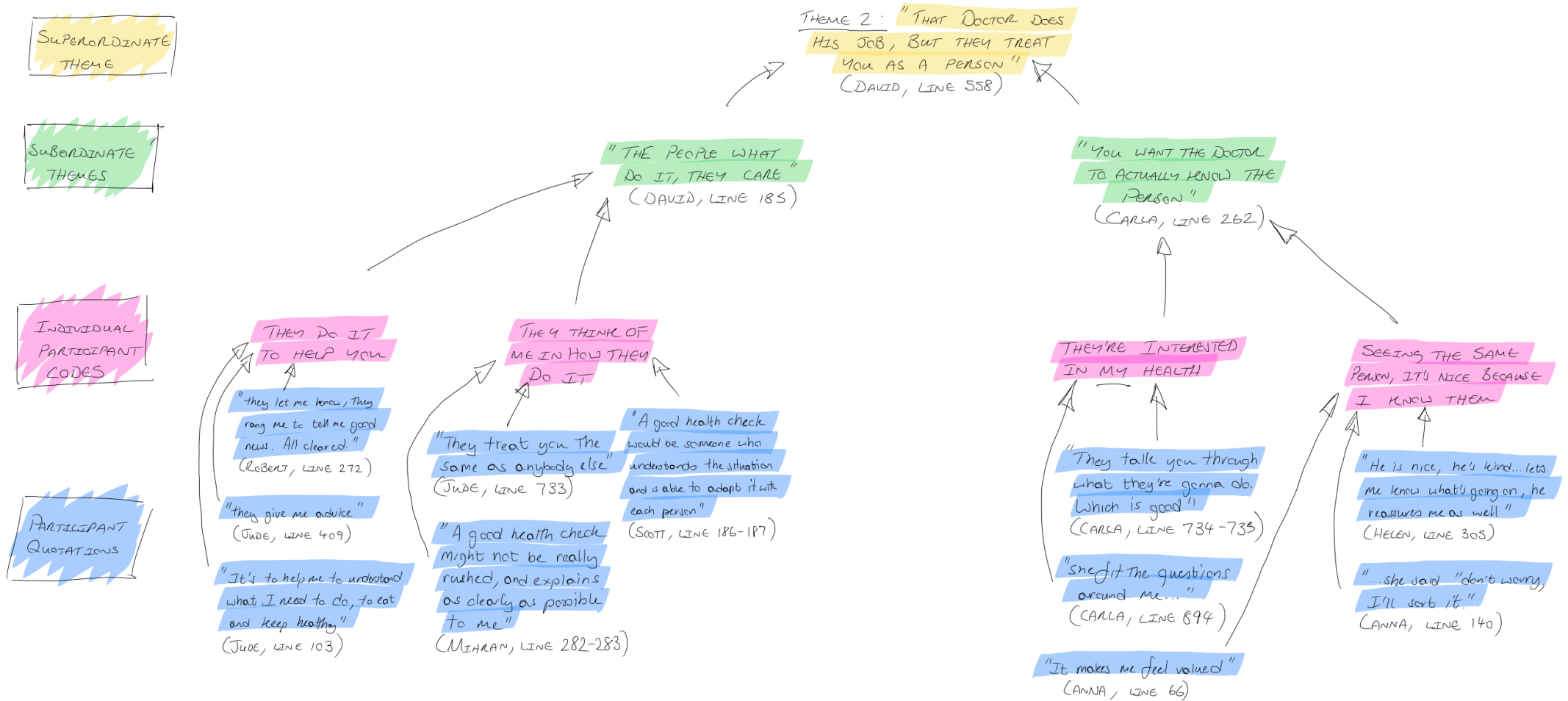
Travel

Question		Yes	No
1	Does any part of the project require data collection off campus? (e.g. work in the field or community)		X
	<p>If YES:</p> <p>You must consider the potential hazards from off campus activities (e.g. working alone, time of data collection, unfamiliar or hazardous locations, using equipment, the terrain, violence or aggression from others). Outline the precautions that will be taken to manage these risks, AS A MINIMUM this must detail how researchers would summon assistance in an emergency when working off campus.</p> <p>For complex or high risk projects you may wish to complete and upload a separate risk assessment</p>		
2	Does any part of the project involve the researcher travelling outside the UK (or to very remote UK locations)?		
	<p>If YES:</p> <p>Please give details of where, when and how you will be travelling. For travel to high risk places you may wish to complete and upload a separate risk assessment</p>		
3	Are all travellers aware of contact numbers for emergency assistance when away (e.g. local emergency assistance, ambulance/local hospital/police, insurance helpline [+44 (0) 2071 737797] and CU's 24/7 emergency line [+44 (0) 2476 888555])?		
4	Are there any travel warnings in place advising against all, or essential only travel to the destination? NOTE: Before travel to countries with 'against all travel', or 'essential only' travel warnings, staff must check with Finance to ensure insurance coverage is not affected. Undergraduate projects in high risk destinations will not be approved		
5	Are there increased risks to health and safety related to the destination? e.g. cultural differences, civil unrest, climate, crime, health outbreaks/concerns, and travel arrangements?		
	If YES, please specify		
6	Do all travelling members of the research team have adequate travel insurance?		
7	Please confirm all travelling researchers have been advised to seek medical advice regarding vaccinations, medical conditions etc, from their GP		

Appendix 2.10: Example of Participant Transcript Analysis

	<u>DESCRIPTIVE</u>	<u>LINGUISTIC</u>	<u>CONCEPTUAL</u>
Jude: And I'm thinking "Here we go again".	Here we go again	Tone suggests boredom/frustration	
Andrew: And, um, how do you, how do you feel when, when you think, "Oh, here we go again"?			
Jude: I was thinking, "Why?" (both laugh) Uh, I think "Aw, I know about that, yeah". You know I agree with them, wholeheartedly, but I say to them "It's up to me when I want to give up". And I say to them "I'm not ready just yet" which they understand. A lot. I do.	Why? We've covered this, I've told you, <u>It's</u> up to me when I want to give up smoking, I agree with them, I know what's healthy and not CHECK: You have your reasons, you explain these reasons, that doc keeps coming back to it sometimes feels pressured to give up, sometimes like they don't listen?	Laughing, tone suggests annoyance Understanding of doctor's point of view, and that it's my choice, my right	Not listening to me, to what I want/choose. Pushing, tension between concern, what's good for health and right to choose.
Andrew: It does feel like, there's a bit of a, sometimes it's, on matters, like the smoking, uh, and that you understand over here (holding one hand up in middle of the screen), why it's good. It would be better for your health, not to, but there are reasons why you keep doing it (<i>raises other hand to meet first hand</i> , symbolising pressures that push the hands to the left and right) and there's, it sounds like there's this bit of, kind off, they're pushing and maybe they push a little too far sometimes, but you understand why. And <u>so</u> the, it kind of, that the experience still stays, would you say it's still a, a good experience or sometimes it goes too far in that...?			
Jude: Sometimes it goes (<i>replicating the push/pull visual metaphor</i>) too far, sometimes. Not all the time. But sometimes it's quite even.	Sometimes they push too far, but sometimes it's even	Balance between left and right hand occupying the middle ground. Represents how sometimes the doctors goal encroaches on my choice.	Physical metaphor of continuum between helpful and pressured, supported and controlling, respected and minimised.
Andrew: It's quite even. When it goes too far, how do you feel? How does that make you feel?			
Jude: Pressured, of giving up sort of thing.	I feel pressured to give up smoking		
Andrew: So pressured?			
Jude: Yeah, and I know in my heart of hearts I'm not ready yet. And I think the doctor's getting the idea now I'm not ready to give up smoking yet. (smiling)	I know I'm not ready. Doctor getting the idea now, has taken them time to learn	Not what the doctor wants – doctor is getting the idea now – <u>doctor</u> slowly understanding? It's taken them time to listen to me, to accept my decision	Efforts to be inclusive and cooperative vs. an approach that discounts and excludes.

Appendix 2.11: Example of Thematic Mapping from Participant Quotes



Appendix 3: Journal submission author instructions

Author Guidelines

Thank you for your interest in *Journal of Intellectual Disability Research*. Please read the complete Author Guidelines carefully prior to submission, including the section on copyright.

Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Content of Author Guidelines:

1. Editorial and Content Considerations
2. Ethical Guidelines
3. Manuscript Types Accepted
4. Preparation of Your Manuscript
5. Submitting Your Manuscript
6. Copyright, Licencing and Online Open
7. Post Acceptance
8. Post Publication

Quick links: [JIDR Submission Site](#), [Wiley's Resources for Journal Authors](#)

1. EDITORIAL AND CONTENT CONSIDERATIONS

The *Journal of Intellectual Disability Research* is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field. JIDR also publishes scientific research on autism where the populations studied have an intellectual disability (or autism, where results are reported on participants with both autism and intellectual disability). Submissions are welcomed from any academic discipline contributing to the scientific study of intellectual disability, on research drawing from several disciplines, or on any topic of relevance to the lives of individuals with intellectual disability. Research questions should be of broad relevance to the scientific field of intellectual disability. Studies using well-reported and robust research methods, including qualitative methods, are welcomed. Papers using systematic literature review methods

and/or syntheses of quantitative or qualitative data are also welcomed. Conceptual papers are not currently accepted. Clinical case reports and descriptions of interventions or service models/programmes containing no evaluation data are generally not published.

The journal publishes Full Reports, Brief Reports and Systematic Reviews. Mental Health Special Editions are published as well as occasional Special Issues (the deadlines for submission for these will be advertised on the journal's website).

Case studies are **not** published by JIDR unless highlighting an important new condition.

Peer Review Process

The acceptance criteria for all papers are the quality and originality of the research and its significance to our readership. Except where otherwise stated, manuscripts are double-blind peer reviewed by at least two anonymous reviewers and an Editor.

Journal of Intellectual Disability Research attempts to keep the review process as short as possible to enable rapid publication of new scientific data. To facilitate this process, submitting authors are asked to suggest the names and current e-mail addresses of two potential reviewers whom you consider capable of reviewing your manuscript. In addition to your choice, the assigned Editor will choose one or two reviewers. Peer reviews will be requested via the submission system. Authors who wish to appeal the decision on their submitted paper may do so by e-mailing the Editorial Office with a detailed explanation for why they find reasons to appeal the decision.

Plagiarism detection

- The journal employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.
- Individual authors and researchers can now check their work for plagiarism before submission - please click [here](#) for details.

2. ETHICAL GUIDELINES

Ethics Statement

During the submission process, all authors must provide an ethics statement. All studies using human participants or animal subjects should include an explicit statement identifying the review and ethics committee approval for each study, if applicable.

Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Journal of Intellectual Disability Research adheres to the ethical guidelines for publication and research summarised below.

Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research.

Journal of Intellectual Disability Research adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). According to the ICMJE authorship criteria should be based on 1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or revising it critically for important intellectual content and 3) final approval of the version to be published. Authors should meet conditions 1, 2 and 3.

It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Authorship by research team members with an intellectual disability is welcomed. In such cases, the guidance for author contributions should be viewed in the context of reasonable adjustments that may be required.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Suppliers of materials should be named and their location (town, state/county, country) included.

The specifications of the source of funding for the study and any potential conflict of interests should be in their own sections as required during the submission process.

Ethical Approvals

See [here](#) for details of Wiley's best practise in research ethics. Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant

with the understanding and written consent of each participant and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used. For manuscripts reporting medical studies involving human participants, we require a statement identifying the ethics committee that approved the study, and that the study conforms to recognized standards, for example: [Declaration of Helsinki](#); [US Federal Policy for the Protection of Human Subjects](#); or [European Medicines Agency Guidelines for Good Clinical Practice](#).

Images and information from individual participants will only be published where the authors have obtained the individual's free prior informed consent. Authors do not need to provide a copy of the consent form to the publisher, however in signing the author confirms that consent has been obtained. Wiley has a [standard patient consent form](#) available for use.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

Randomised Controlled Trials (RCTs)

RCTs should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist (available from the same website) should also be included in the submission material.

Manuscripts reporting results from a RCT must provide the registration number and name of the clinical trial. RCTs can be registered in any of the following free, public trials registries: www.clinicaltrials.gov, clinicaltrials-dev.ifpma.org/, isrctn.org/. The clinical trial registration number and name of the trial register will be published with the paper.

Conflict of Interest

Authors are required to disclose any possible conflict of interest. These include financial (for example patent, ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflicts of interest) will be published under a separate heading entitled 'Conflict of Interests'.

Journal of Intellectual Disability Research requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflicts of interest noted. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of your manuscript.

If the author does not include a conflict of interest statement in the manuscript then the following statement should be included by default: "No conflicts of interest have been

declared".

Source of Funding

Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

If the author does not include a funding information in the manuscript then the following statement will be included by default: "No external funding was received for the research reported in the paper".

Publication Ethics

The journal is a member of, and subscribes to the principles of the [Committee on Publication Ethics \(COPE\)](#). Wiley's Ethics guidelines can also be found at

<http://exchanges.wiley.com/ethicsguidelines>

3. MANUSCRIPT TYPES ACCEPTED

Original Research Articles

The main text should proceed through sections of Abstract (in a Structured format – Background, Methods, Results, Conclusions), and main sections of Background, Methods, Results, and Discussion. Reports of up to 4,500 words are suitable for major studies and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions. Please note that articles exceeding 4,500 words may be unsubmitted immediately from the review process and the authors may be asked to reduce the length of the article. Manuscripts incorporating revisions after review may well be longer than 4,500 words if additional information is requested.

Authors submitting articles should be guided by the following checklists prior to submission:

For observational studies: <http://www.strobe-statement.org/?id=available-checklists>

For diagnostic studies: (http://www.stard-statement.org/checklist_maintext.htm)

Qualitative Studies

Qualitative Studies are only considered if they have strong theoretical underpinnings and use an established method of data synthesis. International reporting guidelines should be used (e.g., <https://www.equator-network.org/reporting-guidelines/coreq/>).

Systematic Reviews

The maximum word length for systematic reviews is 6,000 words. Authors submitting a systematic review are encouraged to assess the quality of their reporting against the PRISMA checklist prior to submission ([http://www.prisma-statement.org/2.1.2 - PRISMA 2009 Checklist.pdf](http://www.prisma-statement.org/2.1.2-PRISMA2009Checklist.pdf)) or MOOSE

guideline (<https://www.equator-network.org/reporting-guidelines/meta-analysis-of-observational-studies-in-epidemiology-a-proposal-for-reporting-meta-analysis-of-observational-studies-in-epidemiology-moose-group/>).

Brief Reports

Brief Reports of up to 2,000 words are encouraged especially for replication studies, methodological research and technical contributions.

4. PREPARATION OF THE MANUSCRIPT

Author Services

Prior to submission, we encourage you to browse the 'Author Resources' section of the Wiley 'Author Services' website [here](#). This site includes useful information covering such topics as copyright matters, ethics and electronic artwork guidelines.

Free Format Submission

The Journal of Intellectual Disability Research now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including statements relating to our ethics and integrity policies (if applicable):
 - o funding statement
 - o conflict of interest disclosure
 - o ethics approval statement
 - o permission to reproduce material from other sources

Writing for Search Engine Optimization

Optimize the search engine results for your paper, so people can find, read and ultimately cite your work. Simply read our best practice [SEO tips](#) – including information on making your title and abstract SEO-friendly, and choosing appropriate keywords.

Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. Visit [our site](#) to learn about the options. All services are paid for and arranged by the author. Please note using the Wiley English Language Editing Service does not guarantee that your paper will be accepted by this journal.

guarantee that your paper will be accepted by this journal.

Spelling

- Spelling should conform to The Concise Oxford Dictionary of Current English.
- A high proportion of papers are submitted with the term 'behavior' as opposed to 'behaviour'; please use 'behaviour'.
- Where applicable the journal standard is to use words ending in -ise as opposed to -ize. For example, use 'analyse' 'standardise' as opposed to 'analyze' and 'standardize'

Units of measurements, symbols and abbreviations should conform with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine. This specifies the use of SI units.

Terminology

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