



Melville, C. et al. (2017) Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities – a systematic review. *Preventive Medicine*, 97, pp. 62-71.  
(doi:[10.1016/j.ypmed.2016.12.052](https://doi.org/10.1016/j.ypmed.2016.12.052))

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Deposited on: 06 January 2017

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# **Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities – a systematic review**

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## **Abstract**

Supporting positive change in lifestyle behaviours is a priority in tackling the health inequalities experienced by adults with intellectual disabilities. In this systematic review, we examine the evidence on the definition, measurement and epidemiology of sedentary behaviour of adults with intellectual disabilities. A systematic literature search of PUBMED, EMBASE, MEDLINE and Google Scholar was performed to identify studies published from 1990 up to October 2015. Nineteen papers met the criteria for inclusion in the systematic review. Many researchers do not distinguish between insufficient physical activity and sedentary behaviour. None of the studies reported the reliability and validity of the methods used to measure sedentary behaviour. Sedentary time, assessed objectively, ranged from 522 to 643 minutes per day: higher than in adults without intellectual disabilities. This first-ever review of sedentary behaviour and intellectual disabilities found that at present the evidence base is weak. Studies calibrating accelerometer data with criterion measures for sedentary behaviour are needed to determine specific cut-off points to measure sedentary behaviour in adults with intellectual disabilities. Researchers should also examine the reliability and validity of using proxy-report questionnaires to measure sedentary behaviour in this group. A better understanding of sedentary behaviour will inform the design of novel interventions to change lifestyle behaviours of adults with intellectual disabilities.

## **Keywords**

Sedentary behaviour, developmental disabilities, obesity, health inequalities, measurement

## Highlights

- This is the first review examining sedentary behaviour and intellectual disabilities.
- Many researchers do not distinguish between sedentary behaviour and insufficient physical activity.
- Adults with intellectual disabilities spend more time sedentary than adults without intellectual disabilities.
- Future research should identify reliable methods to measure sedentary behaviour in this target group.

## Introduction

Intellectual disabilities refer to generalised impairments in intellectual functioning and adaptive behaviour that are present before the age of 18. <sup>1</sup> It is estimated that, internationally, around 2% of adults have intellectual disabilities. <sup>2</sup> Adults with intellectual disabilities are often supported by family or paid carers in their daily living, who may act as role models, provide social support and create a health-promoting environment. Carers have been identified by adults with intellectual disabilities as important facilitators of a healthy lifestyle. <sup>3</sup>

Adults with intellectual disabilities are a particularly vulnerable and, from a health perspective, neglected group in society, experiencing considerable health inequalities relative to the general population. <sup>4</sup> Studies have shown that adults with intellectual disabilities have low levels of physical activity <sup>5</sup> and poor nutritional habits, <sup>6</sup> leading to a high prevalence of obesity and diabetes. <sup>7</sup> This evidence suggests that increasing physical activity and reducing sedentary time are priorities for reducing health inequalities in this group. <sup>8</sup>

Sedentary behaviour has been increasingly recognised as an independent risk factor for premature death and numerous chronic health conditions, including cardiovascular disease, type 2 diabetes and some cancers. <sup>9</sup> The *Sedentary Behaviour Research Network* has defined sedentary behaviour as activities with energy expenditure  $\leq 1.5$  metabolic equivalents (MET) while in a sitting or reclining posture during waking hours. <sup>10</sup> Therefore, sedentary behaviour is distinct from insufficient physical activity, i.e. not meeting physical activity guidelines.

Researchers use different methods to measure sedentary behaviour, and often use proxy measures of total sedentary behaviour, such as time spent watching television (TV). The

most common method of assessment of sedentary behaviour in adults who do not have intellectual disabilities is by self-report, using questionnaires or diaries.<sup>11</sup> The objective assessment of sedentary behaviours, with accelerometers or inclinometers, has also become more common recently. On the one hand, subjective measures are prone to reporting and recall bias but provide a useful context on sedentary behaviours (such as TV viewing and time spent travelling in a car) not collected from objective measures.<sup>12</sup> On the other hand, objective measures are more reliable and accurate, although there is some ambiguity on correct data processing rules and also a lack of validation studies in a real-life setting.<sup>12</sup> Therefore, it is generally recommended to combine both objective and self-report measures.<sup>11</sup>

Owen et al. presented an ecological model which defines four settings where sedentary behaviour takes place: occupation, transport, leisure time and household.<sup>13</sup> According to the ecological model, sedentary behaviour can be divided into four specific domains: a) TV viewing, b) other screen-focused behaviours in domestic environments, c) sitting in the workplace, and d) sitting in cars or public transports.<sup>13</sup> Each of these domains may have distinct determinants. This ecological model provides a multilevel framework to search for determinants from the individual to society level in the general population, as well as in specific groups, such as adults with intellectual disabilities.

We should not assume that our understanding of the relationships between sedentary behaviour and health in adults who do not have intellectual disabilities directly applies to the lives of adults with intellectual disabilities. For example, since only a minority of adults with intellectual disabilities are in paid employment, the evidence around time spent sedentary in work settings has limited relevance to adults with intellectual disabilities. Since sedentary behaviour is now recognised as an important focus of health improvement research, this study aimed to review the evidence on sedentary behaviour of adults with intellectual disabilities and examine the following questions:

- 1) How is sedentary behaviour defined?
- 2) Which methods have been used to measure sedentary behaviour?
- 3) What is the estimated prevalence of sedentary behaviour?

## **Methods**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was used as the basis for this review.<sup>14</sup> A protocol of this systematic literature review was registered with the PROSPERO international prospective register of systematic and given the registration number CRD42015025257.

## **Search strategy**

A search strategy was developed with the help of a biomedical information specialist. The following databases were searched on October 23<sup>rd</sup> 2015: Ovid Medline, Ovid Embase, Web of Science and Google Scholar. The search strategy was based on search terms regarding the following topics: a) intellectual disabilities, b) sedentary behaviour and synonyms (e.g. sedentary lifestyle), and c) types of sedentary behaviour (e.g. TV viewing time, screen time, computer games). The full search strategy is presented in Appendix 1. To identify additional relevant studies, reference lists were hand searched and papers that had cited the final records on Google Scholar were checked to identify any additional relevant studies.

## **Selection of studies**

Observational (cross-sectional, case-control and prospective), experimental (randomised controlled and quasi-experimental) and qualitative study designs were all eligible for inclusion. It was decided that, where the main outcome papers were not yet published,

papers describing intervention study protocols were eligible for inclusion since they might provide details on definitions and measurement of sedentary behaviour.

To be included in the review, studies had to meet the following criteria:

1. Study sample with participants with intellectual disabilities.
2. Study sample 18 years old or over. For studies that included adolescents and adults, at least, 80% of the total sample had to be 18 years or over.
3. For study samples with mixed types of developmental disabilities and data are presented only for the sample as a whole, at least 50% of the sample had to have intellectual disabilities. Studies were excluded if the proportion of participants with intellectual disabilities was not reported.
4. Measures of sedentary behaviour using objective and/or subjective methods.
5. Published in English.
6. Published after 01/01/1990.

Studies were excluded on the basis of the criteria below:

1. The only available record was a conference abstract.
2. The paper reported a lab-based study, e.g. to calibrate accelerometer cut-offs.
3. The authors used the term sedentary to mean a lack of physical activity, e.g. less than 5000 steps per day.

Studies were screened for inclusion using the aforementioned criteria in two stages. In the first stage, the first author and at least one other author independently reviewed the title and abstracts of identified records, with 99.1% agreement and a Cohen's kappa of 0.52. A consensus discussion resolved disagreements about inclusion/ exclusion. In the second



stage, the first author and at least one other author independently and completed inclusion or exclusion checklists for each full text paper. The level of agreement was 86.0% with a Cohen's kappa of 0.72, and disagreement was resolved through a consensus discussion.

### **Data extraction**

A data extraction form was designed specifically for this review, piloted and revised before final use. Since this review was not designed to examine the effectiveness of interventions to change sedentary behaviour, only the baseline data from experimental studies was used to examine the question on prevalence. The first author extracted data from all included studies and two other authors independently extracted data from half of the included articles. Extracted data were compared in meetings and disagreements were resolved through consensus discussion.

### **Quality assessment**

The quality of the included articles was assessed with the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.<sup>15</sup> Each study has a summary score in the range of 0-1.0, with a higher score representing better quality. The first author assessed the quality of all included articles, and two other authors independently assessed the quality of half of the included articles. Disagreements regarding the quality assessment were resolved through a consensus discussion.

### **Results**

Fig. 1 shows the number of articles retrieved and included at each stage of the search process. The majority of full-text articles were excluded because, although the titles and abstracts indicated sedentary behaviour was measured, the studies actually only reported on

not meeting physical activity guidelines or other lack of physical activity, not sedentary behaviour itself.

\*\*\*\*\* insert Figure 1 about here\*\*\*\*\*

### **Study characteristics**

Table 1 provides an outline of the 19 papers included in the data synthesis and the quality ratings for the individual studies.

\*\*\*\*\* insert Table 1 about here\*\*\*\*\*

Eleven cross-sectional and eight prospective, longitudinal studies were included from a range of countries including Scotland (7), United States of America (4), Wales (2), Australia (2), France (2), Norway (1) and England (1). One cross-sectional study reported findings from a large (n=1619) population-based sample,<sup>16</sup> two studies used data from 691 adults living in institutions,<sup>17;18</sup> but the majority of included studies recruited small samples (range 16-96). The mean age of participants in the included studies ranged from 28.5- 48.2 years. Levels of intellectual disabilities were reported in six studies and causes of intellectual disabilities in eight of the included studies.

Table 2 contains the definitions, measurement methods, and prevalence of sedentary behavior reported in each study.

### **Definitions of sedentary behaviour**

Studies included in this review either used a definition that encompasses overall sedentary behaviour or more specific sedentary behaviours, such as TV viewing. Eleven studies focused on overall sedentary behaviour, three used time spent viewing TV or using computers as a proxy definition of sedentary behaviour and four studies included both overall and specific definitions of sedentary behaviours.

### **Methods of measurement**

Several methods for obtaining sedentary behaviours were used, including self- or proxy-report questionnaires, activity diaries, inclinometers, accelerometers, a seven-day recall interview or a combination of more than one method.

Of the 19 included studies, seven studies used self- or proxy-report questionnaires. Five studies used different versions of the IPAQ. The IPAQ- intellectual disabilities (IPAQ-ID) <sup>19</sup> was developed as a proxy-respondent, seven-day recall questionnaire from the long, telephone version of the IPAQ. Four studies used the IPAQ-short version (IPAQ-S). <sup>20-23</sup> Two studies <sup>17;18</sup> adapted the existing French Federation Adapted Sports (FFAS) questionnaire for use with adults with intellectual disabilities. The Longitudinal Health and Intellectual Disabilities study developed a proxy-respondent questionnaire that measured sedentary behaviour by asking informants to rate how many hours a day the participant with intellectual disabilities watched TV. <sup>16</sup> Of all the questionnaires used, the reliability for use with participants with intellectual disabilities was only reported for the adapted FFAS questionnaire, <sup>17;18</sup> which had adequate test-retest reliability when completed by staff working in the institutions where participants lived. However, reliability data was not provided separately for the questions on sedentary behaviours.

Six studies used activity diaries to measure sedentary behaviours. <sup>24;25-29</sup> In developing the International Physical Activity Questionnaire -proxy respondent (IPAQ-pr) <sup>24</sup> the original

IPAQ was changed from a seven-day recall questionnaire to an activity diary for completion by carers and will be discussed with other activity diaries below. Only the IPAQ-pr had reliability and validity for categorising whether the participant met recommendations for physical activity levels, <sup>24;26</sup> not for the measurement of sedentary time. The Bouchard three-day diary was a reliable valid measure of overall energy expenditure <sup>28</sup> and the final two studies found that a seven-day activity diary was not reliable. <sup>25;27</sup>

Regarding objective data, both accelerometers and inclinometers were used. Two studies <sup>24;29</sup> used the ActivPal inclinometer, whereas Actigraph accelerometers were used in nine studies. <sup>20-23;30-34</sup> Studies differed in defined wear time and specific days of the week included. The two inclinometer studies had a seven-day wear time, with a wear time of at least five days being required by Finlayson et al. <sup>29</sup> All nine studies using accelerometers invited participants to wear the accelerometers for seven days. However, the minimum wear time required for inclusion in the analysis varied across the eight studies. In six studies the wear time cut-off for inclusion was three days of six hours <sup>20-23;33;34</sup>, one study required four days of 10 hours wear time for inclusion <sup>32</sup> and two studies did not report the minimum wear time required for inclusion. <sup>30;31</sup> The cut-off used to define sedentary behaviour based on accelerometer counts also differed across studies. Five of the studies that used accelerometers <sup>20-23;33</sup> used a cut-off < 500 counts per minute (cpm), <sup>35</sup> three studies used a cut off < 100 cpm, <sup>31;32;34</sup> and one study did not specify the cut-off to define sedentary behaviour. <sup>30</sup>

Combined objective and subjective data was collected in four studies, <sup>24;20;21;29</sup> with two studies using the combination of inclinometer and activity diaries <sup>24;29</sup> and the other two a combination of accelerometer and questionnaire. <sup>20;21</sup>

One study used interviews and asked adults with intellectual disabilities to recall activities at a day centre, from the last seven days.<sup>36</sup> The activities described were categorized as sedentary behaviours based on energy expenditure using the Compendium of Physical Activities (CPA).<sup>37</sup> Activities like passive transportation, arts and crafts, sewing cushion covers, computer work, snooker, watching TV or videos, reading and writing, cooking, or eating were all defined as sedentary behaviour. Although no quantitative data was reported in this study, this was the only study to measure sedentary behaviour in specific settings,<sup>13</sup> and the only study to highlight the contribution of passive transportation to total sedentary time.

### **Prevalence of sedentary behaviours**

\*\*\*\*\* insert Table 2 about here \*\*\*\*\*

Quantitative measures of sedentary behaviour could only be retrieved from 11 out of the 19 included studies. In three studies, data on sedentary behaviour was collected but not reported,<sup>16;24;26;</sup> in two studies sedentary behaviours were described only qualitatively<sup>29;38</sup> and three studies were protocol papers.<sup>22;23;30</sup>

Based on the accelerometer data, total minutes/day spent in sedentary behaviour in five out of six studies was similar, ranging from 522 to 643 minutes. The exception to this was the study of Finlayson et al. who reported 18.71 h/day (1123 minutes/day) of sedentary time.<sup>29</sup> This high value may be explained by the use of an inclinometer and the use of a one-second epoch, which is more sensitive in the temporal spectrum, compared to the longer epochs (15-60 seconds) in the studies that used accelerometers. With regards to percentage wear time spent sedentary, the results range from 63% to 87.5%. The variation in results is partly explained by the different cut-offs used in these studies. In two of the three studies that used

the lower cut-off point (< 100 cpm), a lower percentage of wear time was spent sedentary (63 – 64%) in comparison to the other studies.

## **Discussion**

This is the first systematic review of the evidence on sedentary behaviour in adults with intellectual disabilities. The majority of studies used overall sedentary time as the definition of sedentary behaviour. Although the feasibility of objectively and subjectively measuring sedentary time using is demonstrated in the included studies, evidence is lacking on the reliability and validity of methods. Our review found that adults with intellectual disabilities are more sedentary than adults without intellectual disabilities.<sup>36</sup>

Our review suggests that researchers in intellectual disabilities and health need to become aware of what is meant by sedentary behaviour. A large number of papers were excluded at the eligibility stage of the study selection process, because they measured lack of physical activity instead of sedentary behaviour. Therefore, many researchers working in the area of intellectual disabilities do not distinguish between insufficient physical activity and sedentary behaviour.

## **Definition of sedentary behaviours**

Studies included in this review used definitions of sedentary behaviour that were similar to those used in the general population. These definitions ranged from overall time spent sedentary, based on accelerometer or inclinometer data, to time spent in specific sedentary behaviours, such as watching TV or using computers. Time spent sitting in cars or other forms of transport is one of the four settings in the ecological model of sedentary behaviour.

<sup>13</sup> Compared to the general population, such passive transportation is often preferred by organisations and paid carers supporting adults with intellectual disabilities because of

safety concerns<sup>37</sup> over more active transportation, such as walking or cycling. Only one included study referred to passive transportation. Studies that do not include passive transportation in their definition are likely to underestimate the total sedentary behaviour time of adults with intellectual disabilities.

### **Measurement of sedentary behaviours**

The complexity and level of abstraction involved in using self-report methods to measure sedentary behaviour is likely to be challenging for many adults with intellectual disabilities. Therefore, most of the studies that used subjective methods to measure sedentary behaviour were dependent on carers or other proxy-respondents to complete the questionnaires or activity diaries. Subjective methods are commonly used because they are a practical, cost-effective way to collect data on sedentary behaviours. However, the practical benefits of using questionnaires and activity diaries have to be considered against the risks of measurement error. For example, sedentary time measured with a proxy-report questionnaire often did not agree with accelerometer data.<sup>21</sup> Some data suggest that the CPA<sup>38</sup> significantly underestimates the expenditure of adults with intellectual disabilities during sedentary behaviours.<sup>39</sup> Additional sources of error are inherent in proxy-report measures of sedentary behaviour compared to self-report. The reliability of carers as proxy-respondents may be limited if they are not with the person 24 hours a day. For example, a paid carer who supports a participant with intellectual disabilities in a day centre that is only open during weekdays will have no knowledge of weekend sedentary behaviours. Family carers may have a broader knowledge of overall sedentary behaviours but may have limited knowledge of sedentary time when their family member was at work or attending a day centre. These gaps in the knowledge of proxy-respondents make it difficult to measure sedentary behaviour across all four settings in the ecological model.<sup>13</sup> Given these potential risks of measurement error, researchers should consider future research to examine

whether proxy-report, or other subjective methods have sufficient reliability and validity to measure sedentary behaviour of adults with intellectual disabilities.

The reliability and validity of using accelerometers to measure total sedentary behaviour have not been established for adults with intellectual disabilities. For example, the widely promoted accelerometer cut-off point of <100 cpm works well to define sedentary behaviour in different population groups.<sup>12</sup> However, no studies have examined the validity of the <100 cpm for adults with intellectual disabilities. Lab-based studies have found that adults with intellectual disabilities expend significantly more energy during sedentary behaviours than adults without intellectual disabilities<sup>19;40</sup> and energy expenditure can be underestimated when using accelerometers to measure sedentary behaviour.<sup>19</sup> The reasons why adults with intellectual disabilities expend more energy during sedentary behaviour are not known. However, overall evidence suggests that a cut-off point at <100pm for sedentary behaviour will significantly underestimate the total sedentary behaviour. Therefore, the three studies that reported significantly higher total sedentary time, based on the < 500 cpm cut-off, provide a more valid measure of sedentary time but this threshold needs to be tested.<sup>20;21;33</sup> Future research on sedentary behaviour using accelerometers and inclinometers need to include adults with intellectual disabilities in order to define and validate appropriate cut-off points for this group.

### **Prevalence of sedentary behaviours**

In studies included in this review, total sedentary time was somewhat higher than in adults without intellectual disabilities.<sup>36</sup> However, most of the studies recruited small samples and none were based on randomly selected samples; therefore, the results are probably not generalisable. The one study that used a large population-based sample of adults with intellectual disabilities<sup>16</sup> collected, but did not report, the actual data for TV viewing time. We are aware of other large epidemiological studies that have also collected, but not reported,



data describing sedentary behaviour in this group.<sup>5</sup> Since, at present, we have minimal knowledge about the sedentary behaviour of adults with intellectual disabilities, we encourage researchers to consider whether they have unpublished data that can add to the evidence base.

### **Strengths and limitations**

A first strength of this review was that PRISMA guidance on methods and reporting of systematic reviews was closely followed. Secondly, the two-stage process to decide on the inclusion of papers, and data extraction were all done in duplicate to maximize reliability. However, the small sample sizes in most of the included studies, and the absence of population based data limits the generalisability of the prevalence of sedentary behaviour data.

### **Future research**

There has been a focus by researchers and policy makers on developing interventions to increase the physical activity levels of adults with intellectual disabilities. This review highlights sedentary behaviour as an equally important area of research to improve lifestyle behaviours of adults with intellectual disabilities. However, since the existing evidence is very weak, more research is needed to develop a better understanding of sedentary behaviour in this group.

Identifying reliable methods to measure the sedentary behaviour of adults with intellectual disabilities is a priority area for research; in the future, both subjective and objective methods should be used. Longitudinal studies of sedentary behaviour should examine its relationship with health. Furthermore, evidence on determinants relevant to changing sedentary behaviour is needed to inform interventions.

## **Conclusions**

This review summarises the existing evidence on sedentary behaviour in individuals with intellectual disabilities. Studies used a wide variety of measurement approaches. Once our knowledge on measurement increases, the priority should be large-scale epidemiological studies to examine possible determinants of sedentary behaviour. Researchers can use the epidemiological evidence to develop effective interventions to reduce the sedentary time of adults with intellectual disabilities.

## **Acknowledgements**

Unrestricted funding to facilitate meetings of the European Network of Physical Activity Research in People with Intellectual Disabilities (ENPARID) was provided by University Ramon Llull and Obra Social La Caixa (reference 2014-URL-Trac-011) to MGB.

## **Conflicts of interest**

None of the authors have any conflicts of interest to declare.

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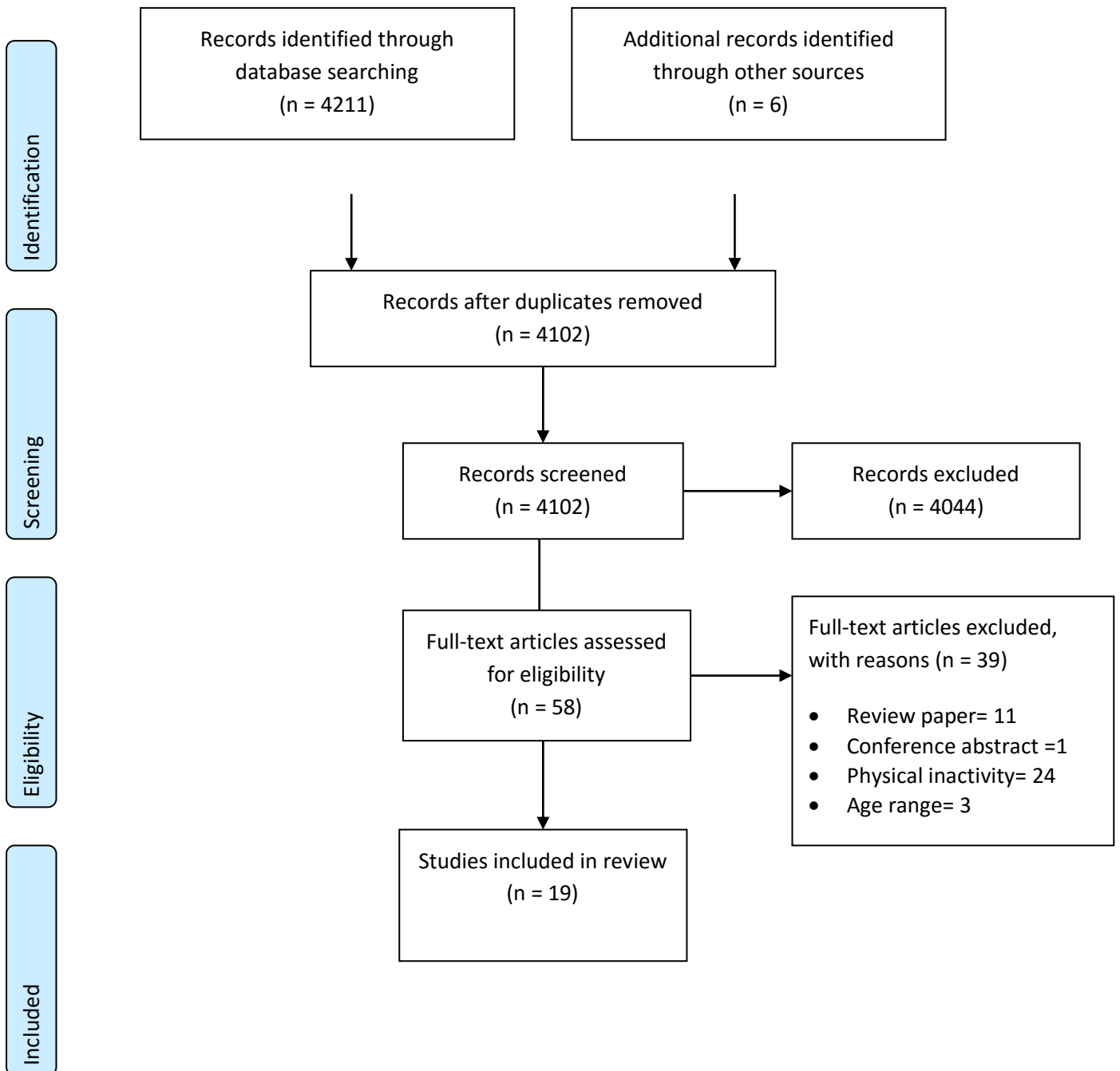
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Figure 1: Flow diagram of study selection process





**Table 1: Characteristics of studies of sedentary behaviours in adults with intellectual disabilities (ID)**

<b>Authors</b>	<b>Setting and target population</b>	<b>Study design</b>	<b>Sample size</b>	<b>Mean age (SD<sup>a</sup>, range)</b>	<b>Gender (% female)</b>	<b>Level of ID</b>	<b>Causes of ID</b>	<b>Mean BMI<sup>p</sup> (SD, range) % obesity</b>	<b>Living circumstances</b>	<b>Quality Score (Range 0-1.0)</b>
Christian Jones (2013) <sup>21</sup>	Wales, all levels of ID using employment and residential services	cross sectional	N = 16	32.8 years (11.1, 19-58);	37.5%	N/A	N/A <sup>c</sup>	BMI= N/A; % obesity= N/A	N/A	.5
Christian Jones (2013) <sup>28</sup>	Wales, all adults with ID supported by providers of residential services	longitudinal-observational	N = 95	41.1 (10.7; 20-65);	35.8%	N/A	5.3% DS <sup>d</sup> , Rett, PWS <sup>e</sup> , Turner, Fragile X, Oral-Facial-Digital, Ring 13 & Moebius syndromes all 1.1%	BMI = N/A; % obesity= N/A	All participants lived in residential settings	.64
Finlayson et al (2011) <sup>31</sup>	Scotland, adults with mild-moderate ID, living in the	cross sectional	N = 62	37.1 (12.8, 18-66)	56.5%	N/A	9.7% DS	BMI = N/A; % overweight = 74.2%	Living independently 3.2%, with family 53.2%, supported living 41.9%, congregate care	.82

	community								1.6%	
Frey et al (2004) <sup>27</sup>	USA, adults living in the community	cross sectional	N = 22	34.9 (SD 9.1),	50%,	N/A	27.3% DS, 4.5% WS <sup>i</sup> , 4.5% Klinefelters syndrome	BMI =34.0 (SD 8.2); % obesity = N/A	Living with parents 31.8%, supported living alone 13.6%, supported living with roommate 22.7%, supported living with spouse 22.7%, supported living in group home 9.1%	.60
Frey et al (2005) <sup>29</sup>	USA, adults with mild ID living in the community	cross sectional	N = 12,	37.0 (6.0, 23-45);	41.7%;	100% mild ID	N/A	BMI = 39 (9, N/A); % overweight = 16.7%, % obesity = 75%	33% living with parents, 16.7% living with spouse, 16.7% living alone, 41.7% living in shared accommodation	.95
Harris et al (2015) <sup>25</sup>	Scotland, individuals with all levels of ID and obesity, living in the community	longitudinal-cluster RCT	N = 66;	N/A	N/A	N/A	N/A	BMI= N/A; % obesity = 100% (BMI ≥30kg/m <sup>2</sup> )	N/A	1.0
Hsieh et	USA, adults	cross	N =	37.1	44.8%	13.3%	24.9% DS	BMI= N/A; %	Own home or	.95

al (2014) 18	with all levels of ID, known to specialist ID organisations	sectional	1619	(14.1, 18-86)		borderline, 31.6% mild, 23.7% moderate, 8.6% severe/profound, 22.8% unknown		overweight= 28.9%, % obesity= 38.3%, % morbid obesity=7.4%	supported living 28.3%, with family member, relative or guardian 57.4%, foster care home or group home 14.3%	
Lante et al (2014) 32	Australia, adults with all levels of ID, living in staff supported housing	longitudinal-RCT	N = 90	N/A	N/A	N/A	N/A	BMI = N/A; % obesity = N/A	N/A	.70
Matthews et al (2011) <sup>25</sup>	Scotland, adults with all levels of ID, living in the community	cross sectional	N = 45	48.3 (12.0, 23-72)	62%;	mild/moderate 66.7%, severe 33.3%	24.4% DS	BMI = N/A; % obesity = 100% (BMI ≥30kg <sup>2</sup> )	N/A	.80
McDermott et al (2012) <sup>33</sup>	USA, community-dwelling adults with mild-moderate ID	longitudinal-RCT	N = 443	38.8 (N/A, 19-70)	50.3%	N/A;	N/A	BMI = 32.5 (18.5-71.3); % overweight = 19.6%, % obesity= 58.9%	Living with family 49.9%, own apartment 3.6% supervised apartment:	.75

									4.7%; group home: 0.5%	
Melville et al (2011) <sup>23</sup>	Scotland, adults with all levels of ID, living in the community	longitudinal-quasi - experimental	N = 54;	48.3 (12.01, 23-71);	59.3%;	mild 31.5%, moderate 31.5%, severe 35.2%, profound 1.9%	24.1% DS	BMI = 40.0 (8.03); % obesity = 100% (BMI ≥30kg/m <sup>2</sup> )	7.4% living independently, 31.5% living with family carers, 61.1% living with support from paid carers	.90
Melville et al (2015) <sup>36</sup>	Scotland, adults with all levels of ID, living in the community	longitudinal-cluster RCT	N = 102	46.3 (12.6)	44.0%	mild 52.6%, moderate 35.3% severe 7.4%	N/A	BMI = 32.4 (7.3); % overweight = 24.1%, % obesity =43.8%, % morbid obesity= 15.1%	Living independently 5.2%, family carer 49.7%, paid carer 43.9%, 2% family carer, 47.9% paid carer	1.0
Messent et al (1998) <sup>38</sup>	England, adults with mild-moderate ID, living in residential homes	cross sectional	N = 24	34.0	41.6%	N/A	N/A	BMI = N/A; % obesity = N/A	29.2% living with parents, 54.2% in shared residential accommodation , 16.6% independently	.27

Mikulovic et al (2014) <sup>19</sup>	France, adults with ID, living in institutions	cross sectional	N = 691	38.1 (10.3, 19-59)	41%	N/A	N/A	BMI = 24.9 (5.4, 13-52); % underweight =7.4%, % overweight= 45.6%, % obesity =17.2%	57% fully residential, 25% half boarders and 18% attended daily	1.0
Mikulovic et al (2014) <sup>20</sup>	France, adults with ID, living in institutions	cross sectional	N = 691	N/A	N/A	N/A	N/A	BMI = N/A; obesity = N/A	N/A	1.0
Mitchell et al (2013) <sup>26</sup>	Scotland, adults with all levels of ID, living in the community	longitudinal-cluster RCT	N = 100; age = N/A; females = N/A; ID level = N/A;	N/A	N/A	N/A	N/A	BMI = N/A; % obesity = N/A	N/A	.80
Nordstrom et al (2013) <sup>34</sup>	Norway, adults with DS, WS and PWS living all over Norway	cross sectional	N = 96	28.5 (7.5)	62.1%;	N/A;	41.7% DS, 29.2% WS and 29.3% PWS	BMI = 30.0 (6.7); % overweight or obese= 78%	25.3% living with parents, 74.7% living in supported community residences	.90

Spanos et al (2015) <sup>35</sup>	Scotland, adults with all levels of ID, living in the community	longitudinal-quasi-experimental	N = 28	N/A	64%	mild 36%, moderate 32%, severe 32%;	29% DS	BMI = 38.2; % obesity = N/A	Living independently 4%, family carer 32%, paid carer 64%	.82
Temple et al (2003) <sup>30</sup>	Australia, adults with mild-moderate ID, living in supported group homes	cross sectional	N = 37	N/A	48.6%	N/A	N/A	BMI = N/A; % obesity = N/A	100% living in group homes	.55

<sup>a</sup> SD standard deviation, <sup>b</sup> BMI measured in kg/ m<sup>2</sup>; <sup>c</sup> N/A not available from the details provided in the paper; <sup>d</sup> Down Syndrome <sup>e</sup> Prader Willi Syndrome <sup>f</sup>

Williams syndrome

**Table 2: Definitions, measurement and prevalence of sedentary behaviours in adults with intellectual disabilities.**

Authors	Study definition of sedentary behaviours	Methods of Measurement		Sedentary behaviour outcome
		Inclinometer/ Accelerometer (make, wear position, wear time, epoch length, sedentary cut-off <sup>a)</sup> )	Questionnaire/ Activity diary (name, reliability, validity, proxy rater)	
Christian Jones et al. (2013) <sup>21</sup>	Total time spent sitting/ sleeping	ActivPAL 3, thigh, 7 day wear time, epoch N/A <sup>b)</sup> , sedentary cut-off N/A	IPAQ-pr <sup>c)</sup> , adequate reliability, good criterion validity, completed by parent or support staff	Sedentary time collected but not reported
Christian Jones et al. (2013) <sup>28</sup>	Total time spent sitting/ sleeping	N/A	IPAQ-pr, adequate reliability, good criterion validity, completed by parent or support staff	Sedentary time collected but not reported
Finlayson et al (2011) <sup>31</sup>	Total time spent in sedentary posture- sitting or lying	ActivPAL, thigh, 7 day wear time (5 days required for inclusion in analysis), epoch= 1s, sedentary cut-off N/A	Study specific diary- activity type and intensity, reliability = N/A; validity = N/A, proxy rater = N/A	Time spent sedentary= total sample 18.71 h/ day (SD <sup>d)</sup> 1.88, range 14.88– 22.19); women 19.56 h/day; men 17. 62 h/day
Frey et al (2004) <sup>27</sup>	TV viewing and computer time	N/A	Study specific activity diary, unreliable during piloting so only used to provide contextual	TV viewing time estimated range 1-

			information, validity =N/A, raters = carers, researchers and participants with ID	5 hours/ day
Frey et al (2005) <sup>29</sup>	TV viewing time	N/A	Study specific activity diary, reliability = N/A, validity= N/A, proxy rater= carers	Reported qualitatively in this paper
Harris et al (2015) <sup>25</sup>	Total sedentary time	Actigraph GT3X, hip, wear time 7 days (3 days x 6 hours for inclusion), epoch= 15s, cut off < 100 cpm	N/A	Protocol paper- results not available
Hsieh et al (2014) <sup>18</sup>	Hours of TV watching (rated 0-9)	N/A	Longitudinal Health and Intellectual Disabilities Study, reliability= N/A, validity= N/A, proxy rater= parents 48%, other relatives 8.5%, health care staff 20.6%, residential/ day programme/ social service /social worker 12.1%, non-related live-in caregiver 3.4%, volunteer 1%	Sedentary time collected but not reported
Lante et al (2014) <sup>32</sup>	Total sedentary time	Actigraph GT1M/ GT3X, right hip, wear time 7 days, epoch N/A, cut off = N/A	IPAQ-ID <sup>e</sup> , Reliability N/A, Validity N/A, proxy rater = carers	Protocol paper- results not available
Matthews et al	1. Total	Actigraph GT1M, hip,	IPAQ-S <sup>f</sup> no reliability	Accelerometer



(2011) <sup>24</sup>	sedentary time 2. Sitting time	wear time 7 days, epoch N/A, cut off < 500 cpm	from ID studies; no validity from ID studies; proxy rater = 26.7% family carers, 73.3% paid carers of 48 months)	10.17 h/ day (SD 2.06), IPAQ-S 9.36 h/ day (SD 3.21)
McDermott et al (2012) <sup>33</sup>	Total sedentary time	Actigraph, waist, wear time 5 days, including 2 weekend days, epoch N/A cut off < 100 cpm	N/A	87.4% of the wear time was spent sedentary
Melville et al (2011) <sup>23</sup>	1. Total sedentary time 2. Sitting time	Actigraph GT1m, hip, wear time 7 days (3 days x 6 hours required for inclusion, epoch 15 seconds, cut off < 500 cpm	IPAQ-S no reliability from ID studies, no validity from ID studies, proxy rater= carers and participants together	Baseline: 1. time spent sedentary 623.3 minutes/ day (SD 121.5) 2. % wear time sedentary 87.5% (SD 8.0), time spent sitting 557.4 minutes/ day (SD 189.4). 3. sitting time (IPAQ- S) 557.4 minutes/ day (SD 189.4)
Melville et al (2015) <sup>36</sup>	Total sedentary time	Actigraph GT3X, waist, wear time 7 days (3 days x 6 hours required for inclusion), epoch N/A, cut off < 100 cpm	N/A	Baseline: intervention group 64.2% wear time sedentary (SD 10.5), control 66.9% (11.3)
Messent et al (1998) <sup>38</sup>	Sedentary behaviours included in a physical activity compendium	N/A	Study specific questionnaire, reliability N/A, Validity N/A, proxy rater= recall by participants with ID and checked with carers	Contextual description of sedentary day centre activities and transportation

				only
Mikulovic et al (2014) <sup>19</sup>	<p>1.Sedentariness = total hours TV and computer / week</p> <p>2.TV watching / day</p> <p>3.Computer or video games/ day</p>	N/A	Questionnaire adapted from French Federation Adapted Sports, reliability= test-retest reliability good (85-90% agreement), validity N/A, proxy rater = educators and nurses	<p>Sedentariness/ week <sup>g</sup> = 18 hours (range 12-28 hours); Time spent watching TV busy days 2 hours (1.5, 3); Time spent watching TV free days 3 hours (2, 4.5); Time spent on computer/ video game busy days 1 hours (1, 2); Time spent on computer/ video games free days 2 hours (1; 3)</p>
Mikulovic et al (2014) <sup>20</sup>	<p>1.Sedentariness = total hours TV and computer per week</p> <p>2.TV watching per day</p> <p>3.Computer or video games/ day</p>	N/A	Questionnaire adapted from French Federation Adapted Sports reliability= test-retest reliability good (85-90% agreement), validity N/A, proxy rater = educators and nurses	<p>Sedentariness (hours/ week)- group 1 <sup>h</sup> = 20.25 (SD 12.25), group 2= 17.75 (SD 12.76), group 3= 23.82 (SD 14.89), group 4= 27.20 (SD 17.46); TV time (mins/ day)- group 1=218 (SD 131), group 2= 180 (SD 1250), group 3= 220 (SD 143), group 4= 225 (SD 130); Computer games (mins/ day) group 1=131 (SD 178), group 2=129</p>

				(SD 71), group 3=163 (SD 116), group 4=172 (SD 130)
Mitchell et al (2013) <sup>26</sup>	Total sedentary time	Actigraph GT3X, hip, wear time= 7 days (3 days x 6 hours required for inclusion), epoch 15 s, cut off < 500 cpm	N/A	Protocol paper
Nordstrom et al (2013) <sup>34</sup>	Total sedentary time	ActiGraph GT3X+, right hip, wear time 7 days (4 days x 10 hours required for inclusion), epoch 60 s, cut off < 100 cpm	N/A	Time spent sedentary= 522 minutes per day (SD 80.3), 63% wear time sedentary
Spanos et al (2015) <sup>35</sup>	Total sedentary time	Actigraph GT1M, hip, wear time 7 days (3 days x 6 hours required for inclusion), epoch 15 s, cut off < 500 cpm	N/A	Baseline= total sedentary time = 576.5 mins/ day (SD 145.9); 84.2% (SD 8.7) wear time spent sedentary
Temple et al (2003) <sup>30</sup>	Total time spent lying and sitting	N/A	Bouchard 3 day Physical Activity, reliability N/A, good validity, proxy rater= paid carers	Time spent sitting and lying= 582.8 mins/ day (SD 122.0)

<sup>a</sup> Cut-offs are expressed as counts per minute (CPM); <sup>b</sup> N/A not available from the details provided in the paper; <sup>c</sup> IPAQ-pr International Physical Activity Questionnaire- Proxy Respondent; <sup>d</sup> SD standard deviation; <sup>e</sup> IPAQ-ID International Physical Activity Questionnaire- Intellectual Disability; <sup>f</sup> IPAQ-S International Physical Activity Questionnaire- Short version; <sup>g</sup> Values are median, quartile 1, quartile 3; <sup>h</sup> Group 1: Early-bed/Early-rise, Group 2: Early-bed/Late-rise, Group 3: Late-bed/Early-rise, Group 4: Late-bed/Late-rise.

## Appendix 1: Search strategy

### Embase and MEDLINE - Ovid, 1990-

Search Terms	Citations Returned
1. exp developmental disorder/ or intellectual impairment/ or exp mental deficiency/ or exp learning disorder/	
2. exp developmental disabilities/ or exp intellectual disability/ or exp learning disorders/ or mentally disabled persons/	
3. exp developmental disabilities/ or exp intellectual development disorder/ or "intellectual development disorder (attitudes toward)"/ or exp learning disabilities	
4. ((intellect\$ adj3 (deficien\$ or difficult\$ or disab\$ or disorder\$ or impair\$ or handicap\$ or incapacit\$ or handicap\$ or sub?average or sub?norm\$)) or (low\$2 adj2 intellect\$)).tw.	
5. (learning adj3 (deficien\$ or difficult\$ or disab\$ or disorder\$ or handicap\$ or impair\$ or incapacit\$ or handicap\$ or sub?average or sub?norm\$)).tw.	
6. (mental\$ adj3 (deficien\$ or disab\$ or handicap\$ or impair\$ or handicap\$ or incapacit\$ or retard\$ or sub?average or sub?norm\$)).tw.	
7. ((subaverage or sub\$1 average or subnormal or sub\$1 normal\$) adj3 (cognit\$ or intel\$)).tw.	
8. ((development\$ or neurodevelopment\$) adj disab\$).tw.	
9. (education\$ adj5 su?bnorm\$).tw.	
10. (cretin\$ or feeble minded\$ or imbecil\$ or moron\$).tw.	
11. Or/ 1-10	
12. Exp sedentary lifestyle/	
13. sedentary behaviour.tw	
14. sedentary behavior.tw	
15. sedentary time.tw	
16. Sedentariness.tw	
17. Physical inactivity.tw	
18. Exp television/	

19.	Exp video games/	
20.	"screen time".tw.	
21.	"sitting time".tw	
22.	"video games".tw.	
23.	"television watching".tw	
24.	"television viewing".tw	
25.	"video viewing".tw	
26.	"electronic game playing".tw	
27.	"computer gaming".tw	
28.	"computer time".tw	
29.	"computer use".tw	
30.	"media time".tw	
31.	"media use".tw	
32.	"web browsing".tw	
33.	"bedroom media".tw	
34.	"electronic media".tw	
35.	"PC".tw	
36.	"PC use".tw	
37.	"occupational sitting".tw	
38.	"deskbound".tw	
39.	"reading".tw	
40.	"motor* transport".tw	
41.	Or/ 12-40	
42.	11 and 41	

### Web of Science

TS= screen time or television or computer games or video games or sitting time or sedentary behaviour or sedentary behaviour or sedentary time or sedentariness or sedentary lifestyle or physical inactivity

AND

TS= intellectual disab\* or intellectual impair\* or developmental disab\* or learning disab\* or mental retard\* or mental handicap\*

### Google scholar

"intellectual disabilities" OR "intellectual disability" OR "developmental disability" or Developmental disabilities" OR "mental retardation" or "Mental handicap" AND "sedentary behaviour" OR "sedentary behaviour" OR "sedentary time" OR "sedentariness" OR "sedentary lifestyle" OR "physical inactivity"

## Appendix 2: PRISMA checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b> Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities – a systematic review			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	35-36
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency	N/A

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8, Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Tables 1 & 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 1
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	12-16
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	15
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	18
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	19