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**TAXONOMY AND PHYSICAL HEALTH INEQUALITIES IN PEOPLE WITH
LEARNING DISABILITIES**

**Section A: Is there a link between diagnostic overshadowing and under-diagnosis of
physical health problems in people with learning disabilities?: Evidence from policy and
research**

Word count: 7,871

**Section B: What can athletes with intellectual disabilities (ID) tell us about taxonomic
frameworks applied to ID?**

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Summary of the Major Research Project

Section A

This narrative review addressed three aims around the research and policy literature on diagnostic overshadowing and under-diagnosis of physical health in people with LD. Systematic searches resulted in seven articles and 20 policies that met the inclusion criteria. These are evaluated and discussed in terms of the review aims. Implications for theory, research and practice are discussed and conclusions drawn.

Section B

This section starts by discussing definitions of intellectual disabilities (ID) and the potential of the International Classification of Functioning, Disability and Health (ICF) as a taxonomic framework to provide a biopsychosocial understanding of ID. An expert panel were consulted to develop an ICF-based questionnaire for people with ID. This was then piloted with athletes with ID using a naturalistic, cross-sectional design, between three pre-existing groups: elite athletes competing through INAS; sub-elite athletes; and athletes with Down syndrome (DS). Seventy-seven athletes took part. The results are discussed in terms of the research questions and hypotheses, including the reliability and validity of the developed questionnaire. Implications for future research are discussed, including suggestions for widening the current competing categories of athletes with ID to include physical health.

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SUZIE LEMMEY BSc (Hons) MSc

Section A: Literature review

**Is there a link between diagnostic overshadowing
and under-diagnosis of physical health problems
in people with learning disabilities?:
Evidence from policy and research**

Word count: 7,871

Abstract

Diagnostic overshadowing in learning disability (LD) is proposed to occur when a person's physical health problem is either overlooked because of, or explained as being part of, a person's LD. This review aimed to examine: the evidence in relation to whether this was associated with under-diagnosis of physical health in people with LD; policies to determine whether this was considered, and if they were consistent with the reviewed evidence base; and whether theories on heuristics and diagnostic overshadowing were supported.

A systematic search of four databases resulted in seven articles that met the inclusion criteria. A further search of two databases and Department of Health websites resulted in 20 policies for review. The research and policy literature could be considered to be consistent, in terms of identifying a link between diagnostic overshadowing and the under-diagnosis of physical health problems in people with LD. However, the narrow research base limited the confidence with which conclusions could be drawn, particularly regarding theory.

In conclusion, there does appear to be a relationship between diagnostic overshadowing and undetected physical health problems in people with LD. In particular, this review has highlighted the need for further empirical, theory-based research.

Keywords: Learning disabilities; physical health; diagnostic overshadowing

1. Introduction

In February 2018, Mencap launched the “Treat me well” campaign to improve the care that people with learning disabilities (LD) receive in hospitals. They reported that “1200 people with a learning disability die avoidably in hospital, each and every year” (Mencap, 2018a, p. 15).

Whilst this figure was based on research they commissioned, this represented an underestimate of the approximated 1,238 to 1,413 amendable and preventable deaths reported (Glover & Emerson, 2013). “Treat me well” followed over 10 years of campaigning by Mencap and other organisations to highlight the issue of substandard physical health care for people with LD.

Whilst the British Psychological Society (BPS) now use the term intellectual disability (ID; 2015), this review used the terms learning disability (LD) and people with LD, as these were more in line with the terminology used in the policy and research covered. The BPS (2015) define ID as a significant impairment in intellectual (IQ less than 70) and social (adaptive behaviour) functioning. Both of these impairments must begin prior to adulthood (i.e. before 18). The only sub-classification that the BPS now recognise is ‘severe’, defined as three standard deviations below the mean on both measures of functioning.

1.1 Diagnostic overshadowing

One of the proposed reasons that health inequalities occur for people with LD is termed ‘diagnostic overshadowing’. Diagnostic overshadowing was first put forward as a concept by Reiss, Levitan, and Szyszko (1982) in relation to mental health in people with LD. They hypothesised that, “intellectual subnormality is such a salient feature of mental retardation that accompanying emotional disturbances are overshadowed in importance by the presence of intellectual retardation” (p. 567). This was based on research using vignettes with clinical

psychologists in America. They found that, if the person in the vignette was said to have a LD, then they were less likely to be diagnosed as having a mental health problem, compared to people with the same mental health symptoms but no LD. Reiss et al. (1982) suggested that this occurred because either the emotional difficulties seemed less pertinent in comparison to the LD, or that they were deemed a direct consequence of the LD. They encouraged the use of case studies to explore this phenomenon further, as they believed that diagnostic overshadowing was more likely to occur in 'real life' situations where clinicians are provided with more, potentially ambiguous, information. Diagnostic overshadowing has proved to be a reliable finding in vignette studies of mental health in people with LD, which have been conducted with a wide range of professionals, including psychiatrists and psychologists (Jopp & Keys, 2001; Mason & Scior, 2004).

In terms of physical health, Jones, Howard and Thornicroft (2008) linked diagnostic overshadowing with premature deaths for people with mental health problems. However, this was not based on specific research, but rather suggestions made from service user and policy reports. Garner and colleagues (1994), in a study with rehabilitation professionals, found that diagnoses of epilepsy, traumatic brain injury or LD all overshadowed the mental health issues in the vignette. Beange, McElduff and Baker (1995) conducted a health screening study of over 200 people with LD in Australia. They found that 95% had associated medical conditions, and 42% had not previously been detected. This was despite them having more doctor and hospital appointments than the general population. The authors suggested that diagnostic overshadowing (using Reiss et al.'s (1982) definition) helped to explain their findings, but this was a post-hoc suggestion.

Therefore, one aim of this paper was to review the evidence in relation to whether diagnostic overshadowing was associated with under-diagnosis of physical health problems in people with LD. As far as could be established, this topic had not been the subject of a review before.

‘Treatment overshadowing’ is proposed to occur when a person is not offered a treatment, such as psychological therapy, because they have a LD (Spengler, Strohmer & Thompson Prout, 1990). However, Spengler and colleagues acknowledged that the issue of treatment overshadowing was complicated by wider issues, such as labelling and availability of treatments, and that there may be a different underlying mechanism at play. Therefore, only diagnostic overshadowing was included in this review.

1.2 Policies and diagnostic overshadowing

Another important area to consider was how policies and national reports address diagnostic overshadowing. It could be argued that, in the emotive area of learning disabilities, policies and reports from organisations such as Mencap have more influence on action at a national level than evidence from research. This was perhaps best illustrated by the report *Winterbourne View – Time for Change* (Bubb, 2014). This report was instigated at the request of NHS England following the public response to a Panorama programme on Winterbourne View, and made recommendations for changes to how services were commissioned.

There has been a precedent for reviewing policies in the area of healthcare for people with LD. In their review, Spackman, Qureshi, and Rai (2016) identified 11 national reports addressing health in people with LD. They found that three included recommendations related to diagnostic overshadowing. This review builds on these findings by conducting a wider literature review specifically looking for diagnostic overshadowing in national policies. These results were then

reviewed in relation to the available research findings on diagnostic overshadowing in the physical health of people with LD.

This methodology was undertaken from the point of view that it is important for policies to be evidence-based. Anderson et al. (2005) argued that the best outcomes are achieved when public health decisions are based on thorough research. Henderson (2012), and Greenhalgh and Russell (2009) pointed out how policy was not always completely based on evidence, as it was influenced by the views and values of politicians, their constituents and the judgements that were made about how to allocate resources. However, Henderson (2012) argued that policy should still be based in evidence. He cited a number of ways in which policy could become vulnerable to what he termed ‘evidence abuse’, such as coming to a conclusion first, or relying on weak results.

This review aimed to determine whether policies for people with LD included diagnostic overshadowing in relation to their physical health and, if so, whether this was grounded in the evidence base. For the purposes of this review, the terms ‘national report’ and ‘policy’ were both referred to as policies within this report. Whilst they are often different reports produced by different organisations, this terminology was used in acknowledgement of both the impact that national reports have on government policy in the United Kingdom (UK), and that not all government documents are termed policies.

1.3 Theories behind diagnostic overshadowing

Morrow and Deidan (1992) set out the precautions that counsellors could take to avoid different kinds of bias when working with clients. They gave different precautions that could be taken to help avoid the different types of potential biases. This helps to illustrate the importance of

understanding the theory behind diagnostic overshadowing, as it may lead to quite different implications, particularly for practice.

One of the biases that Morrow and Deidan (1992) highlighted was the use of heuristics. Kahneman (2011) theorised that people use heuristics as a simple method to find quick, although not perfect, answers to questions. Arguably the two most common heuristics that people use are the 'availability heuristic' and the 'representativeness heuristic', which were first proposed by Tversky and Kahneman (1974). When people use instances that are thought of with minimal effort to assess frequencies or probabilities, they are theorised to be using the availability heuristic. For example, a person might judge how many people with LD there are in the general population by thinking about how many people with LD they know. This heuristic is vulnerable to a number of biases, such as familiarity and salience. Reiss et al. (1982) found that participants attributed the emotional difficulties in the vignettes to the more salient factor (LD), even in the absence of any evidence in the vignette, or any scientific knowledge or theory, to substantiate this. Their research therefore suggested that use of the availability heuristic, and its vulnerability to the salience effect, could lead to diagnostic overshadowing.

However, research findings suggest that saliency does not fully explain diagnostic overshadowing. For example, vignette studies that have altered the severity of LD (arguably making it more or less salient, or noticeable) found no relationship between this and the degree of diagnostic overshadowing (Jopp & Keys, 2001; Spengler et al., 1990).

In the representativeness heuristic, it is theorised that probabilities are evaluated based on how much two groups are judged to be similar; an outcome (e.g. a diagnosis) is selected that is deemed to be most representative of the input (e.g. the description of a person; Tversky & Kahneman, 1974). This is where stereotypes can come into play, as if the description, however

vague, fits a stereotype, then the judgement is likely to be made with confidence. Tversky and Kahneman (1974) termed this the ‘illusion of validity’. The use of this heuristic meant that people were less likely to take into account a number of other factors, such as the base-rate frequency of outcomes (for example the frequency of a certain physical health problem in people with LD), or misconceptions of chance (for example, thinking that because the last three people with LD you saw had a physical health problem, that it is therefore more likely that the next person with a LD that you see will be physically healthy) (Tversky & Kahneman, 1974). The representativeness heuristic, particularly involving stereotyping, was felt to have promise as an explanatory theory to diagnostic overshadowing (Jopp & Keys 2001). For example, Spengler et al. (1990), in their vignette study with rehabilitation counsellors, found that those with more experience were prone to showing more overshadowing in their responses. This was interpreted as the result of stereotypes that had become strengthened over time. However, this finding was found for treatment overshadowing, and therefore may not also be the case for diagnostic overshadowing.

It is important to note that the case for the applicability of this theory to diagnostic overshadowing in LD had so far only been in relation to mental health. It cannot be assumed that the same processes apply in both mental and physical health. Nevertheless, this theoretical framework had the potential to explain diagnostic overshadowing that may be observed in relation to physical health and LD. Therefore, a second aim of this review was to examine whether there was evidence to support the applicability of the use of one, or both, of the availability heuristic and the representativeness heuristic, here.

1.4 Summary and aims

In summary, this review had three aims:

1. To review the evidence in relation to whether diagnostic overshadowing was associated with under-diagnosis of physical health problems in people with LD.
2. To review the policy evidence to determine:
 - a. whether this considered diagnostic overshadowing in relation to physical health for people with LD and, if so,
 - b. whether this was consistent with the reviewed evidence base.
3. To review whether there was evidence to support the applicability of theories on heuristics to this area (this is covered in the Discussion).

To meet these aims, a narrative review based on a systematic search of the research and policy literature was used.

2. Methodology

2.1 Aim 1: Search of the research literature

Four databases were used: PsycINFO; Medline; The Cumulative Index to Nursing and Allied Health Literature (CINAHL); and Web of Science – Social Sciences Citation Index (SSCI).

These databases were chosen to help ensure that articles from all relevant professions would be covered. Searches of titles, abstracts and keywords (or equivalent) were made using the search terms in Table 1. In order to be as inclusive as possible, no limits were set on publication dates. The search was conducted in October 2017.

To be eligible for inclusion, articles had to be in the English language. Articles that were not peer-reviewed, including book chapters, were excluded, as were non-research

articles (such as editorials and descriptive articles). The articles were then read in full to ensure that they met further inclusion criteria of:

- specifically addressing people with LD;
- including diagnostic overshadowing;
 - and that this was in the context of physical health (and not, for example, just in relation to mental health or dementia).

At this stage articles were also excluded if diagnostic overshadowing was not a clear focus or outcome of the research; for example, if it was mentioned once incidentally.

Table 1:

Search terms used and how they were combined

	<u>PsycINFO</u>	<u>Medline</u>	<u>CINAHL</u>	<u>SSCI</u>
Searches conducted on:	Abstract and Key Concepts	Abstract and Keyword Heading	Abstract and Subject	Topic
Search terms used	“intellectual* dis*” OR “learning dis*” OR “mental* retard*” OR “intellectual* impair*” OR “development* dis*” OR “cog* impair*” OR “mental* handicap*” AND Overshadow*			
Limits	English language			

* indicates truncation

Figure 1 illustrates the search strategy that was used. To help ensure that articles were not missed, additional searches were conducted on articles that were referenced, in relation to diagnostic overshadowing, in the final policies and articles in Tables 3 and 4. Searches were conducted for articles that had cited the final articles used. An additional search using Google

Scholar was also performed, using the search term “diagnostic overshadowing learning disabilities”. These additional searches resulted in another five articles being included.

Finally, the eight articles were reviewed to ensure they were of sufficient quality for inclusion. This was done using the criteria relevant to the methodology used, namely Yin’s (2014) case study criteria and the Critical Appraisal Skills Programme Qualitative Research Checklist (CASP, 2017; see Tables i & ii in Appendix A). This process resulted in one article being omitted as, using Yin’s criteria, it lacked sufficient information to be considered a case study. This left seven articles for review. Tuffrey-Wijne (2002) met all of Yin’s (2014) case study criteria, and Ali et al. (2013) met the most of the CASP (2017) criteria.

2.2 Aim 2: Search of the policy literature

For this search, the databases Social Policy and Practice and The King's Fund Library Database were used. These two were the only known databases to include policies. A search was also made of Department of Health and Social Care publications on the www.gov.uk website. Due to the small number of retrieved results when “overshadowing” was used as a search term, searches were conducted using different terms for learning disabilities and database-dependant methods for restricting findings to policies (Table 2). No limits were set on publication dates; historic policy documents were also included to allow for the potential for an historic narrative to be identified. This search was conducted in November 2017.

To be eligible for inclusion, policies had to be in the English language and from the UK. To help ensure that the policies were continuing to have reach and impact, they had to be accessible online. Policies were searched in full to ensure that they met the inclusion criteria using the same methodology used for research (see section 2.1). Figure 2 illustrates the search strategy that was

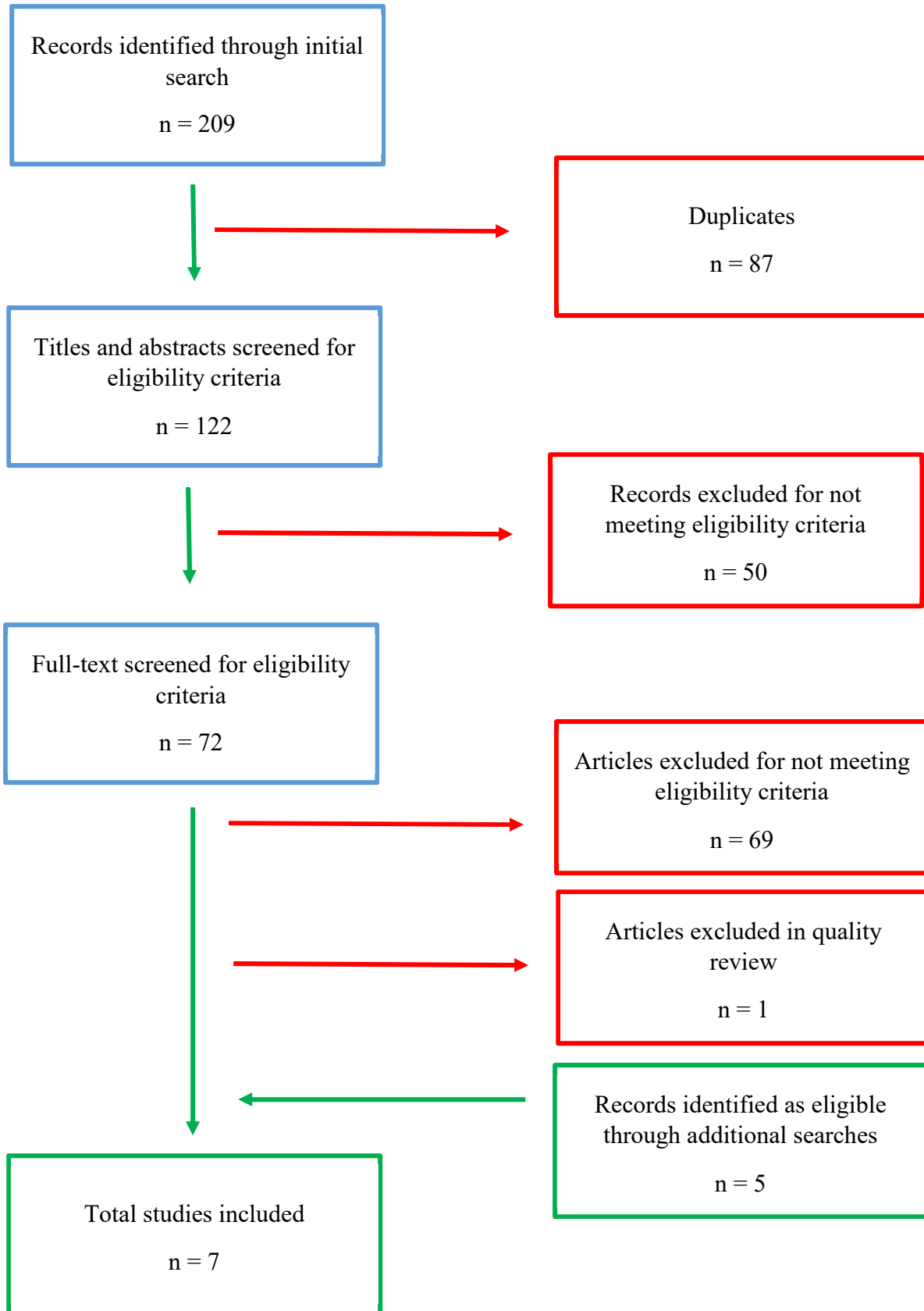


Figure 1: Flow chart showing literature search strategy for articles

used. To help ensure that policies were not missed, additional searches were conducted on the titles of policies that were referenced in either the final policies or the final research articles found (Tables 3 & 4). To help ensure that the whole of the UK was covered, additional searches were made for ‘diagnostic overshadowing’ and a separate search for ‘learning disability’ on: the Health in Wales document search webpage (<http://www.wales.nhs.uk/documentsearch>); the NHS Scotland publications webpage (<http://www.scot.nhs.uk/publications/>); and the Department of Health, Northern Ireland publications webpage (<https://www.health-ni.gov.uk/publications>). These additional searches resulted in seven more policies being included.

Table 2:

Search terms used and how they were combined

	<u>Social Policy and Practice</u>	<u>The King's Fund Library Database</u>	<u>www.gov.uk website</u>
Search terms used	“intellectual* dis*” OR “learning dis*” OR “mental* retard*” OR “intellectual* impair*” OR “development* dis*” OR “cog* impair*” OR “mental* handicap*”		‘learning disability’
Limits		English language	
	Search restricted to: ‘Online reports’ and ‘Reports’	Search restricted to: annual report or King’s fund publication or official memorandum or publication from a project supported by a King’s Fund grant or web publication Subject: Health	Department of Health and Social Care publications

* *indicates truncation*

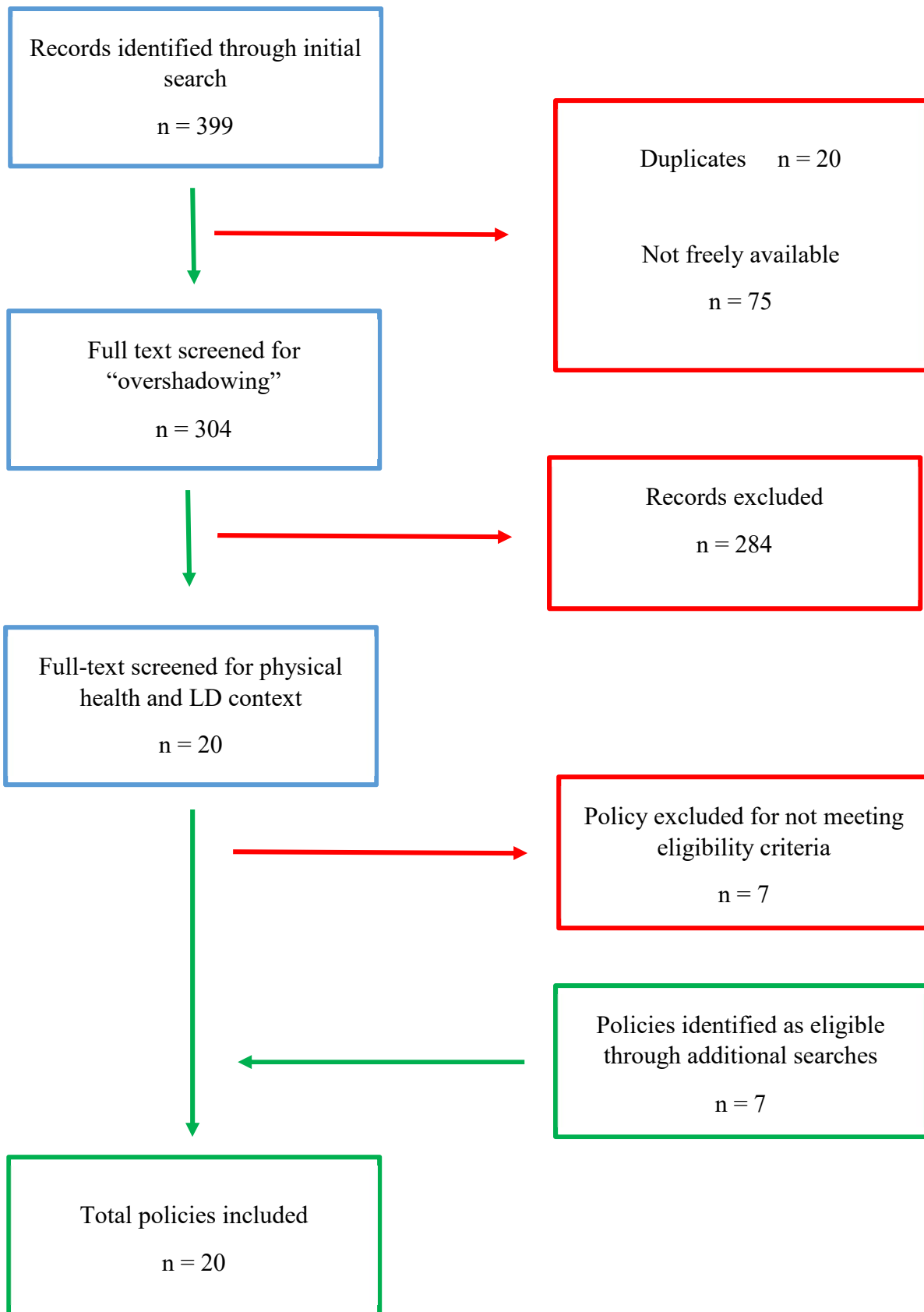


Figure 2: Flow chart showing literature search strategy for policies

3. Results

3.1 Overview of the research

The research is summarised in Table 3. Given that many articles looking at diagnostic overshadowing in mental health and LD use vignettes (Jones et al., 2008) it was notable that this methodology was not used when it came to research on physical health in this population. Instead, all the articles used qualitative methods, including two case studies.

Both the case studies covered people with LD and palliative care. Brown, Burns and Flynn, (2003) included 21 people with LD in their study, with the aim of establishing whether services had allowed them to have an ‘ordinary’ death. Their methodology was extensive, involving interviews with a range of professional staff, service users and family members, plus a community LD team audit of deaths amongst their clients. This produced rich data to draw from, but arguably too much data to allow a full discussion of all the themes within one article. Two cases were spoken about in depth; one person with epilepsy; and one with bowel cancer. Diagnostic overshadowing was cited as a reason for a delay in diagnosis in both cases. However, it was unclear how these cases were chosen for inclusion. The study’s conclusions focused on the impact on staff of working with someone who is dying.

Tuffrey-Wijne (2002) reported on a more in-depth study with a person with LD, with the aim of identifying palliative care needs for this population. This study also included interviews with staff and with the subject of the case study. No family members were included. Five themes were discussed: the delay in seeking medical attention, attributed to diagnostic overshadowing; confusion around consent; difficulties between family and paid carers; provision of physical care; and a reluctance to talk about death. These themes were well illustrated with examples, and the article as a whole was more grounded in the research literature than Brown et al. (2003).

Table 3:
Summary table of the seven articles resulting from the literature search

<u>Authors</u>	<u>Study design</u>	<u>Participant details</u>	<u>Context</u>
Tuffrey-Wijne (2002)	Case study	A 54-year old man living in a residential home, diagnosed with Down syndrome and cryptogenic cirrhosis	Palliative care in a residential home in England
Brown, Burns & Flynn (2003)	Case studies series	21 people with LD. 10 male. Aged between 22 and 80 at time of death. Diagnoses included: Down syndrome (5); 'Severe' LD (1); 'Moderate' LD (7); 'Mild' LD (4); 'Multiple physical and cognitive impairments' (2); Cerebral palsy (2); Epilepsy; Dementia (1); Cancer (9); Pneumonia (2); Emphysema; Respiratory difficulties (2)	Provision of palliative care across different agencies in the London area.
Sowney & Barr (2006)	Focus groups	27 registered nurses with at least one years' experience working in five accident and emergency departments.	Accident and emergency departments in Northern Ireland
Minnes & Steiner (2009)	Grounded theory analysis of semi-structured focus group interviews	Parents and carers of children with fragile X syndrome, autism or Down syndrome, aged 5 to 47.	Healthcare services in Ontario, Canada
Dinsmore (2011)	Thematic analysis of 12 semi-structured interviews	Two people with LD, 3 people with LD and their carer, and 7 carers. Age range of people with LD 8 to 51. Participants had 'mild' to 'severe' LD and a range of physical health problems, including epilepsy, diabetes, and kidney problems.	Recent hospital experience on Merseyside.
Ali et al. (2013)	Thematic analysis of 29 semi-structured interviews	14 patient-carer pairs, and one single carer. Patients were aged between 23-57; equal numbers males and females; 9 were White British/Other, 5 were Asian Indian/Pakistani. Carers were aged between 28 and 72 and the majority were mothers. Participants with LD had 'mild' or 'moderate' LD and a range of physical health problems, including cerebral palsy, epilepsy (2), diabetes (2), hypertension (2) and asthma (2).	Primary care, inpatient and community secondary care health services, within London and two English NHS Trusts
While & Clark (2014)	Multimethod: interviews and focus groups; development and piloting of a competency tool	Interviews with: 9 senior LD nurses, 5 parent/nurses, 1 parent, 8 people with LD, 1 consultant psychiatrist, 1 consultant psychologist, 1 psychiatric liaison nurse, 1 speech and language therapist, 1 advocate and 9 senior nurses. Focus groups with: 11 members of community and mental health LD teams; 6 medical modern matrons; 8 people with LD; advocates. Piloted with 34 nurses in a general hospital	General hospital, London

The remaining studies used interviews and focus groups to investigate themes that arose in relation to people with LD accessing and using health care. Ali et al. (2013) and Dinsmore (2011) used thematic analysis to explore interviews with people with LD and family carers. Ali et al. (2013) spoke to most people with LD with their carer, and Dinsmore (2011) also did this in three cases. Whilst this may have had advantages, for example in helping the person with LD to communicate, it also may have prevented the person with LD from feeling able to be completely open and honest in the interviews. In both studies semi-structured interviews were used, and Dinsmore (2011) specifically included diagnostic overshadowing as an interview topic. Ali et al. (2013) reported seven themes under three topics: barriers to healthcare; discrimination from healthcare; and good practice. They produced 15 recommendations to address these. Dinsmore (2011) reported 11 themes (including provision of and awareness of reasonable adjustments, and staff attitudes), and accompanying recommendations. Both studies used examples well to support their findings.

Minnes and Steiner (2009) conducted a grounded theory analysis of semi-structured focus group interviews with parents and carers of children with fragile X syndrome, autism or Down syndrome. Their research was conducted in Canada, making it the only non-UK study. Again, a semi-structured interview format was used, but no examples of research questions were provided. Five emergent themes were discussed for children with fragile X syndrome and children with Down syndrome, with the role of parents and the need for further education of healthcare staff being common to both.

While and Clark (2014) conducted interviews and focus group with people with LD, parents, carers and a wide range of healthcare staff. These were based on a literature-led topic guide, but no examples of questions were provided. The results also did not use any examples from these;

instead, this section focused on the main aim of the study, which was to develop and pilot a competency tool for adult trained nurses on working with people with LD. This was in the context of a lack of competencies or guidelines for including education on learning disability for adult nurses. The resulting competency tool encompassed 74 items across 12 domains, including: assessment of pain; consent; understanding of LD; and communicating with people with LD and others. On piloting this tool with 34 nurses a range of educational needs were identified, most commonly for: diagnostic overshadowing; how mental and physical health problems interact; and environmental adaptations for people with a diagnosis of autism.

Sowney and Barr (2006) looked at the challenges that accident and emergency (A&E) nurses in Northern Ireland reported around treating people with LD. Consideration was given to inter-rater reliability in the analysis, but it was unclear what methodology was used. The semi-structured format resulted in six themes, although only two were discussed in detail: lack of knowledge; and dependence on carers. These were well supported by the data. However, exploration of the other themes, particularly communication difficulties, may have resulted in further discussion of diagnostic overshadowing.

A number of further limitations applied across the majority of the studies. Apart from in the case studies, most of the participants in the study were female. With the exception of Ali et al. (2013), where most of the participants were described as White, there was a lack of detail on ethnicity across the studies. Whilst people with 'severe' LD were included in Dinsmore (2011) and Brown et al. (2003), this was limited to two people and one person respectively. Over half the qualitative studies had a small sample, and potential recruitment biases (Dinsmore, 2011; Minnes & Steiner, 2009; While & Clark, 2014). Furthermore, these five studies had generally not met CASP (2017) guidance in terms of adequate consideration of the role of the researcher and

potential biases (with Ali et al. (2013) being a notable exception here). These issues limit the generalisability of these findings.

3.2 Aim 1: Was diagnostic overshadowing associated with under-diagnosis of physical health problems in people with LD in the research literature?

Ali et al. (2013) found that substandard care was reported by nearly all participants. This included diagnostic overshadowing, where behaviour was attributed to the LD, resulting in one case in irreversible neurological damage. Minnes and Steiner (2009) reported that diagnostic overshadowing was referred to by all the parents of children with Down Syndrome (DS), but not by those of children with either Fragile X or autism. Parents linked this to stereotypes of people with DS as being compliant and non-complaining.

Tuffrey-Wijne (2002) gave arguably the best illustration of diagnostic overshadowing in practice in her case study, where faecal incontinence had been viewed as a behaviour that challenges, and therefore attributed to the person's LD. The author concluded that this diagnostic overshadowing delayed the diagnosis of his terminal physical health problem. She linked this to other findings in the literature (Reiss & Szysko, 1983; Howells, 1997), and used these to support her definition of diagnostic overshadowing as, "where behavioural manifestations of discomfort are attributed to the patient's underlying intellectual disability or perhaps to his/her challenging behaviour, rather than to an undiagnosed physical illness" (p. 223).

3.2.1 Staff knowledge. Sowney and Barr (2006) found that A&E nurses reported a lack of knowledge regarding ID, and that this affected their confidence and competence in caring for this population. They linked this to diagnostic overshadowing, as their lack of understanding might result in a person with LD's behaviour being attributed to the LD, rather than a sign of a physical

health problem. However, they also found that nurse's fear of missing something could lead to over-investigation. While and Clark (2014) also highlighted reported lack of knowledge by nursing staff. Overshadowing was covered in two domains in their piloted competency tool: assessment and care planning ('Know the interplay between physical and mental health and the role that 'behavioural overshadowing' may have in this' and 'Understand 'diagnostic overshadowing' and the impact that it may have on the assessment process) and assessment of pain ('Understand issue of 'diagnostic overshadowing' and impact on accurate assessment of pain'). In the pilot, the majority of nurses reported a lack of knowledge around diagnostic overshadowing. A significant number also felt this applied to specific health problems associated with LD.

Brown et al. (2003) concluded that a lack of knowledge amongst healthcare staff led to diagnostic overshadowing. For example, in one case hospital staff had assumed that the person with LD could not mobilise because of their LD, when this was not the case. A lack of knowledge was also highlighted in other studies, but not explicitly linked to diagnostic overshadowing (Ali et al., 2013; Dinsmore, 2011; Minnes & Steiner, 2009; Tuffrey-Wijne, 2002).

3.2.2 Communication. Both Brown et al. (2003) and Dinsmore (2011) related communication between healthcare staff and carers (family or paid) with diagnostic overshadowing. Dinsmore (2011) provided two clear examples of where family member's interpretation of the people with LD's expression of pain were ignored by healthcare staff, and pain was instead attributed to the LD. In the Brown et al. (2003) example above, a resolution was only achieved after the intervention of someone who knew the client well instigating communication with ward staff.

However, whilst the majority of the research studies reported issues around communication, it was often unclear whether this led to under-diagnosis of physical health problems in people with LD directly, or via diagnostic overshadowing. Ali et al. (2013) reported problems with communication as a barrier to care, including people with LD feeling ignored, and lack of accessible information (also highlighted by Dinsmore, 2011). Ali et al., (2013), Dinsmore (2011) and Minnes and Steiner (2009) found that parents felt they had to be ‘pushy’, and that their knowledge about the person with LD was often disregarded. While and Clark (2014) included this issue in their competency tool, both under communication with people with LD, and with carers, other professionals and agencies. Brown et al. (2003) highlighted how communication issues could arise when clients moved services, due to new staff not being made aware of ‘reference points’ or the subtleties around a person with LD’s communication style.

3.2.3 Further barriers and issues. Diagnostic overshadowing was only one of the potential reasons for under-diagnosis of physical health problems in people with LD reported in the research. Negative staff attitudes were highlighted in several studies (Ali et al., 2013; Minnes & Steiner, 2009; Tuffrey-Wijne, 2002). Participants in Dinsmore’s (2011) study also reported a lack of empathy and understanding amongst staff. They linked this to lack of experience and specialist training, but not diagnostic overshadowing.

Issues around consent, such as ‘Best Interest’ decisions, were raised in four articles (Brown et al., 2003; Sowney & Barr, 2006; Tuffrey-Wijne, 2002; While & Clark, 2014). Other barriers mentioned by more than one article were: problems with accessing help (Ali et al., 2013; Minnes & Steiner, 2009); stress in and between healthcare staff and carers (Ali et al., 2013; Brown et al., 2003; Tuffrey-Wijne, 2002); and discussing death with people with LD (Brown et al., 2003; Tuffrey-Wijne, 2002).

This was also reflected in the range of recommendations made in the research. The most common recommendations were: training in communication skills; annual health checks; involvement of carers; and involvement of liaison nurses. Using the evidence provided by the reviewed studies, half of these recommendations could be related to diagnostic overshadowing (lack of training and carer involvement).

3.2.4 Summary. A search of the literature resulted in seven relevant articles being reviewed; two case studies and five qualitative studies. These studies had limitations which made it difficult to generalise their findings to the wider LD population. The research outlined how diagnostic overshadowing could result in under-diagnosis of physical health problems in people with LD, from multiple perspectives. However, they also highlighted several other factors that may have an impact here. Consequently, whilst diagnostic overshadowing is undoubtedly only part of a larger issue of the health inequalities the people with LD face, it appears to be perceived as a significant one.

3.3 Overview of the policy literature

Details of the 20 policies identified through the search are included in Table 4. These spanned over a decade, between 2004 and 2015. They were from 11 different organisations, with the most represented being the Department of Health (DoH) and Mencap, with three each. The origin of the policies was frequently linked to previous ones. For example, the Disability Rights Commission (DRC, 2006; 2007) policies led to an independent inquiry (Michael, 2008). This in turn led to the DoH funding a three-year project, the Learning Disabilities Public Health Observatory, which resulted in two further policies (Emerson & Baines, 2010; Turner, 2011).

Authors of three policies conducted their own research on which to base their findings; the National Patient Safety Agency (NPSA, 2004); the DRC (2006), which had the most mentioned of diagnostic overshadowing (11); and Michael (2008) (see Table 4 for details). The NPSA (2004) and DRC (2006) policies referred to their websites for details on both methodology and results. Unfortunately, neither organisation now exist (the NPSA was transferred to the NHS Commissioning Board Special Health Authority in 2012, and the DRC was replaced by the Equality and Human Rights Commission in 2007). As a result, their websites no longer exist; however, it is still possible to find some of the results online.

The Area Studies Report to the DRC (Samele et al., 2006) outlines how their methodology included studying GP clinical data sets, focus groups and interviews with people with a mental health problem and people with a 'learning difficulty', and telephone interviews with health care managers, practitioners and advocates. They spoke to 69 mental health service users and eight carers, from a range of ethnic backgrounds. By contrast, they spoke to 30 people with LD and six carers; all White British or White European. There was a separate report from the Welsh Centre for Learning Disabilities (Kerr, Felce & Felce, 2005) which conducted five focus groups with people with LD. However, due to the websites being decommissioned it is unclear whether all the results from the studies that contributed to these policies were found, or if similar reports for mental health service users were completed. The fact that the full methodology also remains unclear means that it is hard to evaluate the quality of the findings, or to replicate them.

This is complicated further by the fact that both the DRC (2006; 2007) and the British Medical Association (BMA, 2014) policies cover both people with LD and people who use mental health services. The DRC highlighted the health inequalities that both groups face as their reasoning for this approach, and the BMA cited the use of this approach by the DRC. However, this may add

Table 4:

Summary table of the 20 policy and national reports resulting from the literature search

<u>Author and year</u>	<u>Report title</u>	<u>Type of report and evidence used</u>	<u>No. times over-shadowing mentioned</u>	<u>How overshadowing is discussed in the report</u>	<u>Recommendations directly linked to overshadowing</u>
Mencap (2004)	Treat me right! Better healthcare for people with a learning disability.	Charity report addressing health inequalities for people with LD. Uses case studies.	1	Reports experiences of families where doctors “believe their health problem is as a result of the learning disability and that not much can be done about it” (p. 13). States diagnostic overshadowing as “well documented” (p. 13) by the Down’s Syndrome Association (1999) and the National Patient Safety Agency (NPSA, 2004). Describes diagnostic overshadowing as “dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability.” (Holland, 2000) (p. 13). Two case illustrations.	N/A
National Patient Safety Agency (2004)	Understanding the patient safety issues for people with learning disabilities	Report based on a literature review, and workshops and interviews with 46 people with LD and 12 family carers, and focus groups with 150 health and social care staff.	2	Covered under patient safety priority 5: “Illness or disease being mis or un-diagnosed”. Uses Holland (2000) definition of diagnostic overshadowing. Two examples from focus groups with staff, of a missed diagnosis that led to death from kidney failure and a misdiagnosis that could have led to loss of sight.	N/A
Disability Rights Commission (DRC; 2006)	Equal treatment: Closing the gap.	A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental	11	Definition: “reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated.” (p. 6) Whole section on ‘diagnostic overshadowing’ (their quotes, p. 69). This phenomenon had been mentioned by ‘many’ who took part in consultations, “particularly by people with	Reported that a cultural shift was needed to make individual adjustments the norm along with raised expectations for health outcomes. Recommended that governments in England

		health problems. Refers to their website for methodology		mental health problems”. However, families and people with LD reported that physical health symptoms had been attributed to behavioural problems.	and Wales should spearhead, with partners, medical and nursing training at all levels to explicitly address diagnostic overshadowing. They also recommended that this should be incentivised through the GP appraisal system.
DRC (2007)	Equal Treatment: Closing the Gap - One Year On	Progress report	7	Definition: “Diagnostic overshadowing refers to the tendency of health and social care professionals and others to interpret the reporting of symptoms, and symptoms themselves, to a learning disability or mental health problem.” (p. 5) Cites Mencap (2007). Reports some progress on action addressed at tackling diagnostic overshadowing, including training with the British Medical Association (BMA), General Medical Council (GMC), Royal College of Psychiatrists (RCPsych) and Equip Cymru. They reports more needed to be done to make this national and at all stages of training and qualification, including forming part of appraisal systems.	Included recommendations that the (then-upcoming) Michael inquiry cover diagnostic overshadowing. “Recommendation 11: There should be a comprehensive programme of evidence based training and information resources (the design and at least some of the delivery of which involves users and user groups) for primary health care staff... We suggest the DH more actively considers addressing ‘diagnostic overshadowing’ through the professional appraisal system to ensure, in particular, changes in GP practice.” (p. 42)

Mencap (2007)	Death by indifference	Treat me right! report follow up. Case studies	4	Quotes the Disability Rights Commission report (DRC; 2006).	None
Secretary of State for Health (2008)	A Life Like Any Other? Human Rights of Adults with Learning Disabilities	Government Response to the Joint Committee on Human Rights	1	“Under the leadership of the Promoting Equality steering group, we are working with the EHRCs and with professional, regulatory and educational bodies to improve the way that learning disability is addressed in undergraduate and postgraduate curricula, for instance in relation to diagnostic overshadowing.” (p. 10)	N/A
Michael (2008)	Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities	Independent inquiry. Findings based on: public consultation (including staff, carers and people with LD); literature review; evidence from witnesses and stakeholders	6	Cites DRC (2006). Reported that witnesses, professionals and carers told them diagnostic overshadowing was “widespread”, particularly in palliative care, or when pain was communicated through behaviour experienced as challenging (p. 18). Witnesses reported a potential cause as ignorance regarding LD. The inquiry concluded diagnostic overshadowing should be urgently addressed.	Recommended competence-based mandatory training in learning disabilities in undergraduate and postgraduate clinical training, and that this should involve people with learning disabilities and their carers.
Giraud-Saunders (2009)	Equal access? A practical guide for the NHS	Guidance on creating a Single Equality Scheme that includes improving access for people with LD	1	“Clinicians need to guard against ‘diagnostic overshadowing’ and ensure that signs and symptoms are not mistakenly attributed to the person’s learning disability.” (p. 12).	None
HM Government (2009a)	Valuing People Now: ‘Making it happen for everyone’	Impact Assessment Report	1	Cited Healthcare for All report (Michael, 2008)	None
Emerson & Baines (2010)	Health Inequalities & People with Learning	Briefing paper	1	“A range of organisational barriers to accessing healthcare services have been identified (Michael, 2008; DRC, 2006; Giraud-Saunders, 2009; Kwok & Cheung, 2007; Alborz, McNally &, Glendinning, 2005; Alborz, McNally &	N/A

	Disabilities in the UK: 2010			Swallow, 2003). These include: ...‘diagnostic overshadowing’ (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities)” (p. 9)	
Department of Health (2010a)	Six lives: Progress report	Progress report	1	Highlights an ambulance service that includes diagnostic overshadowing in staff training	None
Department of Health (2010b)	Valuing People Now	Summary Report March 2009-September 2010	1	As above.	
Royal College of Psychiatrists (2010)	No health without mental health: The supporting evidence	Report	3 (two mental health)	Highlighted dangers of diagnostic overshadowing in terms of: clinicians (and carers) dismissing manifestations of pain, delirium, or problems with hearing and vision, as they were attributed to the person’s learning disability. Cited Lavis, Cullen, and Roy (2009). Highlighted inadequacies of current training, leading to clinicians (particularly GPs) lacking in confidence and knowledge, particularly regarding capacity and consent, and liaison services. They also highlighted additional barriers, such as communication skills and time.	N/A
Royal College of Nursing (RCN, 2011)	Meeting the health needs of people with learning disabilities	RCN guidance for nursing staff	1	“Signs and symptoms, such as incontinence, can be attributed to the person’s learning disabilities rather than other causes, including ill health. This is known as ‘diagnostic overshadowing’.” (p. 6)	N/A
Turner (2011)	Health inequalities and people with learning disabilities in the UK: 2011.	Evidence into practice report no. 4	1	Highlighted barriers to care for people with LD, including: lack of reasonable adjustments; “disablist attitudes among health care staff, and ‘diagnostic overshadowing’ (when symptoms of ill health are mistaken for behavioural problems or as being part of the person’s learning disability)” (p. 11).	None

Mencap (2012).	Death by indifference: 74 deaths and counting.	Progress report, based on case studies	1		None
British Medical Association (2014)	Recognising the importance of physical health in mental health and intellectual disability: Achieving parity of outcomes	Stated that the report was intended for policy makers in health and social care, as well as doctors and other professionals	4	Referred to diagnostic overshadowing as “symptoms of physical ill health being mistakenly attributed to either a mental health problem or as being inherent to the person’s intellectual disability (or vice versa). [Emerson & Baines (2010)].” (p. 32). Highlighted how carers can also make similar assumptions, or be unaware of the significance of particular symptom. Cites Death by Indifference report (Mencap, 2007), Michael (2008) report and Valuing People Now (HM Government, 2009b). Acknowledges paucity of research in mental health and diagnostic overshadowing. Did not mention or use any peer-reviewed research for LD. Highlighted how allowing more time for appointments could allow more exploration of presenting problems and therefore reduce the risk of diagnostic overshadowing.	Recommended integrating mental health and intellectual disability into the core curriculum in undergraduate and postgraduate medical training, and that, “Training in intellectual disability that explicitly tackles ‘diagnostic overshadowing’ and unequal treatment should be integrated at undergraduate, postgraduate and continuing professional development levels.” (p. 64)
SeeAbility (2015)	An equal right to sight: why eye care for children with learning disabilities needs reform	Children in Focus Campaign report, based on research from delivering specialist sight tests in selected special schools	2	“...identification of sight problems is often symptom led and behaviour may be wrongly attributed to the diagnosis of learning disability, rather than a sight problem (known as ‘diagnostic overshadowing’).” (p. 3)	None
Department of Health (2015)	Government response to No voice unheard, no right ignored	Government response – a consultation for people with learning disabilities, autism	1	None	“We intend to clarify the roles and responsibilities in guidance for commissioners in relation to supporting people with learning disabilities, autism and mental health

		and mental health conditions		conditions [in order to] address issues of premature mortality, co-morbidities, diagnostic overshadowing.” (p. 30).
The Scottish Government (2017)	5 year survey of need for mental health inpatient care for children and young people in Scotland with learning disability and/or autism: Full report	Government report, in conjunction with NHS Scotland, Mental Welfare Commission and Kindred	1	“Barriers for children and young people with learning disabilities to accessing appropriate mental health services include: ... ‘Diagnostic overshadowing’, where presenting problems are ascribed to a child’s learning disability alone, rather than looking at other, potentially treatable physical or mental health causes.” (p. 123)

NOTE: some quotes have been amended to use APA referencing style.

to the confusion around the difference between mental health and LD that different charities and researchers cite as problematic (Mencap, 2018b; Thomas & Woods, 2003). It also casts doubts on the specificity of the findings and recommendations of these policies to the LD population.

3.4 Aim 2a: Do the identified policies consider diagnostic overshadowing in relation to physical health for people with LD?

Diagnostic overshadowing in relation to physical health was mentioned in the main text in 19 policies, with one policy just including it in its recommendations section. Overall it was mentioned in just over a quarter (five) of policy recommendations. The majority reported that healthcare staff attributed the health problem to the LD, leading to diagnostic overshadowing through no diagnosis being given, or misdiagnosis of symptoms (Mencap, 2004; NPSA, 2004; DRC, 2006; 2007; Giraud-Saunders, 2009; Emerson & Baines, 2010; Royal College of Psychiatrists (RCPsych), 2010; Royal College of Nursing, 2011; Turner, 2011; BMA, 2014; SeeAbility, 2015). Michael (2008) added to this by highlighting the ignorance of professionals when it comes to LD, and how diagnostic overshadowing was a particular problem in palliative care and when people with LD were in pain.

The most common recommendation in relation to diagnostic overshadowing was for further training for nurses and medics specifically aimed at diagnostic overshadowing (three), followed by closing the health inequality gap (two) and GP appraisal systems (two). Further recommendations related to diagnostic overshadowing, mentioned once across the policies, were: the need for a cultural shift; raising expectations for improved health outcomes; further training for nurses and medics on LD; covering diagnostic overshadowing in inquiry reports; and clarifying the roles and responsibilities of commissioners. The BMA (2014) policy suggested a

more holistic approach to training doctors, integrating physical and mental health alongside learning disability as part of the core curriculum. They stated:

“This holistic approach to care should help to challenge diagnostic overshadowing and undermine any assumptions that mental health and intellectual disability patients have to live with poorer physical health.” (p. 61)

3.5 Aims 2b: Is the inclusion of diagnostic overshadowing in the identified policies consistent with the reviewed evidence base?

Only three policies speculated on what might be leading to diagnostic overshadowing occurring. Michael (2008) and the RCPsych (2010) linked it to lack of knowledge in healthcare staff regarding LD, and highlighted the need for training to address this. This was consistent with the evidence base, as it currently stands. However, the RCPsych and the BMA (2014) also highlighted how carers can lack knowledge when it comes to interpreting particular physical health symptoms, and claimed that this could also result in diagnostic overshadowing. This was not a finding that was found in the research covered in this review. These reports did not conduct their own research on which to base these claims.

When discussing diagnostic overshadowing there was a notable lack of research citations across the policies. Eight policies did not use any references when they mentioned diagnostic overshadowing. This included the DRC policies, which defined diagnostic overshadowing as, “reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated.” (p. 6). The majority of the others (apart from Emerson & Baines, 2010; RCPsych, 2010) referenced other policies, mostly the DRC (2006) and Michael (2008). Whilst these two were based on their own research findings, this suggests a lack

of other available research in this area. This was acknowledged in the BMA policy (2014), which did not mention or use any peer-reviewed research for LD.

As in the policy literature, the reviewed articles frequently referred to policies as opposed to research. For example, Dinsmore (2011) linked his findings to Michael (2008). While and Clark (2014) also linked their findings to this, and to *Death by Indifference* (Mencap, 2007). It could appear as though circular arguments are starting to form around both the research and policy literature, with neither building on an actual evidence base.

3.6 Summary of the policy literature

Twenty policies were found that mentioned diagnostic overshadowing. Some of these just mentioned it once as a concept (for example DoH, 2015; the Scottish Government, 2017). However, it could be argued that this treatment of diagnostic overshadowing in the policy literature gives the impression that it is an undisputed cause of under-diagnosis of physical health in people with LD, when there is a lack of research evidence to completely support this.

Others, notably policies that incorporated their own research, gave more space to the concept (for example DRC, 2006; Michael, 2008). However, the findings from the influential DRC policy are limited by the lack of availability of research findings and addressing diagnostic overshadowing in people with LD and people with mental health issues simultaneously. Additionally, the underpinning research literature was rarely cited. Overall, as with the research literature, diagnostic overshadowing was one of several proposed reasons for the under-diagnosis of physical health problems in people with LD.

4. Discussion

This paper aimed to review the evidence in relation to three aims: whether diagnostic overshadowing was associated with under-diagnosis of physical health in people with LD in the research literature; whether the policy evidence considered diagnostic overshadowing in relation to physical health for people with LD and, if so, whether this was consistent with the reviewed evidence base; and whether there was evidence to support the applicability of theories on heuristics to this area. These aims are discussed below, along with the limitations to these findings and the possible implications for research and practice.

4.1 Aim 1: Was diagnostic overshadowing associated with under-diagnosis of physical health problems in people with LD in the research literature?

Seven research articles were reviewed to help to answer this research question. The number of articles found limits the confidence with which conclusions can be made here, as do the small, nondiverse samples used. Despite these limitations, health problems going undetected in people with LD was well established from the research evidence presented. However, the reasons for this remained unclear. Additionally, as only qualitative articles were found, it might be considered inappropriate to talk about an association between diagnostic overshadowing and under-diagnosis of physical health problems in people with LD. This term has henceforth been changed to 'relationship'.

Diagnostic overshadowing appears to be one of several possible factors contributing to the under-diagnosis of physical health problems in this population. It may also be that these factors are not mutually exclusive, particularly with communication. More research is therefore needed

to help illuminate this issue further. In particular, the qualitative literature covered in this review could provide a grounding for future empirical studies.

4.2 Aim 2a: Did policies consider diagnostic overshadowing in relation to physical health for people with LD?

Twenty policies mentioned diagnostic overshadowing in the context of undetected physical health problems in people with LD. A quarter of these went on to make recommendations in this area, most commonly for further training for healthcare professionals on LD and diagnostic overshadowing. However, these findings were complicated by some policies combining the issues of people with LD with mental health service users. The policies also largely did not refer to any research literature.

4.3 Aims 2b: Was the policy literature consistent with the reviewed evidence base?

The policy literature could be considered to be consistent with the reviewed evidence base, in terms of identifying a link between diagnostic overshadowing and the under-diagnosis of physical health problems in people with LD. Whilst only three policies expanded on this further to consider the causal mechanisms for this, this was also broadly in line with the research literature in terms of suggesting that this was due to a lack of knowledge on LD amongst healthcare staff, and providing recommendations regarding further training.

However, it could be argued that diagnostic overshadowing is talked about with too much conviction in policies, with both policy and research relying too heavily on policy findings and recommendations rather than peer-reviewed empirical research.

4.4 Aim 3: What does the available evidence inform us about the theory behind diagnostic overshadowing?

The most commonly linked factor to diagnostic overshadowing, across both policies and articles, was the lack of staff knowledge regarding learning disabilities (Brown et al., 2003; Michael, 2008; RCPsych, 2010; Sowney & Barr, 2006; Tuffrey-Wijne, 2002; While & Clark, 2014). This is consistent with the possibility that staff may be compensating for their lack of knowledge by using a heuristic. The fact that this finding held across a range of difficulties for people with LD suggests that saliency, and therefore the availability heuristic, could not fully explain the results (Jopp & Keys, 2001; Spengler et al., 1990). The best fit appeared to be the representativeness heuristic, particularly the use of stereotypes. This also corresponded with Minnes and Steiner's (2009) findings regarding staff stereotyping children with Down syndrome.

Kahneman (2011) theorised that stereotypes are how people think of social groups. They could lead people to interpret another's behaviour in a way that fit with their pre-held stereotype (Clements, 1997). This helped to explain the examples found in this review where a person with LD's expression of pain was seen as 'challenging behaviour', and therefore attributed to the LD rather than a potential underlying physical health problem. Spengler et al. (1990), in their work on diagnostic overshadowing within mental health, reported that stereotyping is a strong bias, whereby over time information that fits the stereotype is assimilated, and that which does not is disregarded. They concluded that this could help to explain instances where diagnostic overshadowing occurred in more experienced professionals, or for people with 'mild' learning disabilities.

However, there is a distinct lack of research in this field to help establish if this is the case within physical health. This heuristic also struggles to explain the findings of Sowney and Barr

(2006), where staff became over-cautious, leading them to take steps to avoid diagnostic overshadowing by, for example, ordering more medical tests to ensure that they were not missing a physical health problem.

Another finding linked to diagnostic overshadowing was communication with carers (Brown et al., 2003; Dinsmore, 2011). This could be explained by the concept of cognitive complexity (Spengler & Strohmer, 1994), in which people are theorised to rely less on heuristics, leading them to seek out other sources of information, such as that from carers. Spengler and Strohmer (1994) found that clinicians who demonstrated lower cognitive complexity were more likely to demonstrate diagnostic overshadowing. However, whilst this theory has promise, the mechanisms behind this theory that may lead to diagnostic overshadowing remain unclear. Overall, a pertinent issue with the policy and research evidence presented has been the lack of integrating theory. This therefore undermines the confidence with which the implications have been made, as theory is needed to provide a basis for effective interventions (Morrow & Deidan, 1992).

4.5 Limitations of the review

There are several limitations to this review that should be considered when drawing conclusions about the results. More research articles were found through alternate searches rather than the systematic search itself. It could be suggested that this indicated a limitation to this review, potentially in terms of an inefficient search strategy. Research on diagnostic overshadowing in the mental health and LD field addressed diagnostic overshadowing more explicitly, often including the term in the title (for example Mason & Scior, 2004; Reiss et al., 1982). However, this was not the case for articles on physical health and people with LD, where diagnostic

overshadowing was often an emerging theme from qualitative research. This meant that the term was less likely to appear in systematic searches of abstracts and keywords. However, the thorough additional searches of the literature (both policy and research) that were made resulted in increased confidence in the completeness of the included research articles.

A criticism of the literature on diagnostic overshadowing of mental health in people with LD has been the over-reliance on vignette-based research (Jones et al., 2008). The use of qualitative methods can therefore be seen to counter this, and to answer the request for more in-vivo studies (White et al., 1995). However, the narrow range of methods used in the articles found can be seen as a limitation to the research results, particularly given the lack of opportunities that it provided to compare with findings from research in the mental health field. It might also be argued that the results are limited as they report the perceptions of participants, rather than experimental evidence (Ali et al., 2013).

4.6 Implications for practice

The most common recommendation from the policies and articles was for further training for healthcare staff regarding learning disabilities, and particularly around communication issues. There is a role for clinical psychologists here in helping ensure that training programmes cover this sufficiently and efficiently. Clinical psychologists are also well placed to conduct this in a theory-based way, when there is further research to support this. This is particularly relevant given that mental health research has suggested that education alone produces short-lived changes in attitudes (Corrigan, Morris, Michaels, Rafacz, & Rüschi, 2012). It is therefore important for clinical psychologists to be aware of these limitations and to be able to make

evidence-based suggestions for improvement, such as the involvement of people with LD (Scior & Werner, 2015).

Regarding the potential for communication issues to interact with diagnostic overshadowing, clinical psychologists are also well placed in teams to act as mediators to help staff and carers to work together efficiently, to help both sides feel that they are heard. They can also work alongside colleagues, notably speech and language therapists, to help others consider how people with LD may be trying to communicate physical health symptoms through verbal and non-verbal methods.

This paper also holds implications for writers of policy in this area. It appeared that policies in this review had become vulnerable to a number of ‘evidence abuses’ (Henderson, 2012). The findings suggest that policy in this area should become more evidence-based, in order to help reduce inequalities in healthcare for people with LD (Anderson et al., 2005).

4.7 Implications for research

The qualitative and case study research in this review provided a solid grounding for more focused research on diagnostic overshadowing of physical health in people with LD. This could be through vignette research, using a methodology similar to that used in mental health research in this area (for example Reiss et al., 1982; Mason & Scior, 2004). In addition there could be other, more ecologically valid, methods worth considering. This includes recording of actual sessions, for example with GPs (there is precedent for this approach, taken with psychiatrists [Quirk, Chaplin, Lelliott & Seale, 2011]), or of sessions with actors (for example Schulman et al., 1999). Research could also be done to explore the impact of the implementation of the

recommendations made on diagnostic overshadowing. For example, does further training in LD actually lead to a decrease in this occurring?

It may be argued that, given the complexities of the issues around physical health inequalities for people with LD, that an entirely different approach is needed. One approach would be to address attitudes and stigma around people with LD. However, the majority of research in this area to date has been limited by the methodology used, lack of connection with theory, and small effect sizes (Scior & Werner, 2015). The BMA (2014) and Howells (1997) argued for the need for a holistic approach to care that encapsulates LD and physical and mental health as a way of addressing diagnostic overshadowing. Research could therefore look at widening the current, medical model view of people with LD.

One way of doing this would be to consider LD as a taxonomy. Fleishman and Quaintance (1984) defined taxonomies as “theoretically based language systems” (p. vii) that enable concepts to be categorised. Building a taxonomy of LD would allow the current definition to be broadened to include physical health alongside IQ and adaptive functioning (Nakken & Vlaskamp, 2007). The use of the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001) has potential here, as it was produced with the specific aim of providing a holistic view of a person’s physical health, their ability to participate in activities, and contextual factors (environmental and personal) that may impact upon this and their general wellbeing. Barnes and Mercer (2010) described the ICF as incorporating a taxonomy aligned with the medical model, allowing for meaningful research to be conducted, but also incorporating the social model of disability through inclusion of environmental barriers. They therefore aligned it to a critical realist biopsychosocial model. It might be hypothesised that this wider definition of LD would help professionals to provide more holistic care for people

with LD by providing a concrete taxonomy to use, reducing reliance on stereotypes and thus, potentially, reducing diagnostic overshadowing of physical health problems in people with LD.

5. Conclusion

There does appear to be a relationship between diagnostic overshadowing and undetected physical health problems in people with LD. However, there is insufficient research in this area to warrant the confidence with which it has been spoken of in policies. In addition, both policies and research highlight how diagnostic overshadowing is one part of the health inequalities that people with LDs face. More work needs to be done, by researchers and by policy makers, to ensure that people with LD are treated with respect within our healthcare system and that they receive the physical healthcare treatment they need. In particular, this review has highlighted the need for further empirical, theory-based research.

6. References

- Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy, 10*, 173–82. doi:10.1258/1355819054338997
- Alborz, A., McNally, R., & Swallow, A. (2003). *From the Cradle to the Grave: a literature review of access to health care for people with learning disabilities across the lifespan*. Retrieved from: http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1210-023_V01.pdf
- Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS ONE, 8*. doi:10.1371/journal.pone.0070855
- Anderson, L.M., Brownson, R.C., Fullilove, M.T., Teutsch, S.M., Novick, L.F., Fielding, J., & Land, G.H. (2005). Evidence-based public health policy and practice: promises and limits. *American Journal of Preventive Medicine, 28*(5 Suppl), S26–S30. doi:10.1016/j.amepre.2005.02.014
- Barnes, C., & Mercer, G. (2010). *Exploring disability* (2nd ed.). Cambridge: Polity.
- Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: a population study. *American Journal of Mental Retardation 99*, 595–604. Available from: <http://psycnet.apa.org/record/1995-37447-001>
- Bishop, K.M., Robinson, L.M., & VanLare, S. (2013). Healthy aging for older adults with intellectual and developmental disabilities. *Journal of Psychosocial Nursing, 51*, 15-18. doi:10.3928/02793695-20121218-02

- British Medical Association. (2014). *Recognising the importance of physical health in mental health and intellectual disability: Achieving parity of outcomes*. Retrieved from: <https://www.bma.org.uk/connecting-doctors/search?q=Recognising%20the%20importance%20of%20physical%20health%20in%20mental%20health%20and%20intellectual%20disability#serpq=Recognising%20the%20importance%20of%20physical%20health%20in%20mental%20health%20and%20intellectual%20disability>
- British Psychological Society (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. Available from: <https://shop.bps.org.uk/guidance-on-the-assessment-and-diagnosis-of-intellectual-disabilities-in-adulthood.html>
- Brown, H., Burns, S., & Flynn, M. (2003). "‘Please don't let it Happen on my Shift!’ Supporting Staff who are Caring for People with Learning Disabilities who are Dying", *Tizard Learning Disability Review*, 8, pp.32-41. <https://doi.org/10.1108/13595474200300016>
- Bubb, S. (2014). *Winterbourne View – Time for change. Transforming the commissioning of services for people with learning disabilities and/or autism*. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>
- Clements, J. (1997). Challenging needs and problematic behaviour. In J O'Hara & A. Sperlinger (Eds.), *Adults with Learning Disabilities: A Practical Approach for Health Professionals* (pp. 61–79). Chichester: John Wiley and Sons.
- Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsçh, M. (2012). Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric Services*, 63, 963-973. doi:10.1176/appi.ps.005292011

Critical Appraisal Skills Programme. (2017). *CASP Qualitative Research Checklist*. Retrieved from: http://docs.wixstatic.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf

Department of Health. (2010a). *Six lives: Progress report*. Retrieved from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216180/dh_120494.pdf

Department of Health. (2010b). *Valuing People Now: Summary Report March 2009 - September 2010*. Retrieved from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

Department of Health. (2015). *Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions*.

Retrieved from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/475155/Gvt_Resp_Acc.pdf

Dinsmore, A.P. (2012). A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: speaking with patients and their carers. *British Journal of Learning Disabilities*, 40, 201–212. <https://doi.org/10.1111/j.1468-3156.2011.00694.x>

Disability Rights Commission. (2006). *Equal treatment: Closing the gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Retrieved from: <http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf>

Disability Rights Commission. (2007). *Equal treatment: Closing the gap - one year on. Report of the reconvened Formal Inquiry Panel of the DRC's Formal Investigation into the*

inequalities in physical health experienced by people with mental health problems and learning disabilities. Retrieved from:

<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/DRC-closing-the-gap-fi.pdf>

Down's Syndrome Association. (1999). *He'll never join the army: A report on a Down's Syndrome Association survey into attitudes to people with Down's syndrome amongst medical professionals*. Retrieved from:

<https://www.lemosandcrane.co.uk/dev/resources/Down's%20Syndrome%20Association%20-%20He'll%20never%20join%20the%20army.pdf>

Emerson, E., & Baines, S. (2010). *Health Inequalities & People with Learning Disabilities in the UK: 2010*. Retrieved from:

https://pure.strath.ac.uk/portal/files/7402206/vid_7479_IHaL2010_3HealthInequality2010.pdf.

Fleishman, E. A., & Quaintance, M. K. (1984). *Taxonomies of human performance: The description of human tasks*. Orlando: Harcourt Brace Jovanovich.

Garner, W.A., Strohmer, D.C., Langford, C.A., & Boas, G.J. (1994). Diagnostic and treatment overshadowing bias across disabilities: are rehabilitation professionals immune. *Journal of Applied Rehabilitation Counseling*, 25, 33-37. Available from:

<http://psycnet.apa.org/record/1995-01787-001>

Giraud-Saunders, A. (2009). *Equal access? A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities*.

Retrieved from: [http:](http://)

[//webarchive.nationalarchives.gov.uk/20130123200911/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753](http://webarchive.nationalarchives.gov.uk/20130123200911/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753)

- Glover, G., & Emerson, E. (2013). Estimating how many deaths of people with learning disabilities in England could be prevented by better medical care. *Tizard Learning Disability Review*, 18, 146-149. <https://doi.org/10.1108/TLDR-03-2013-0025>
- Greenhalgh, T., & Russell, J. (2009). Evidence-based policymaking: a critique. *Perspectives in Biology and Medicine*, 52, 304–18. doi:10.1353/pbm.0.0085
- Henderson, M. (2012). *The geek manifesto: Why science matters*. London: Bantam Press.
- HM Government. (2009a). *Valuing people now: 'Making it happen for everyone'. Impact assessment report*. Retrieved from:
http://www.legislation.gov.uk/ukia/2009/12/pdfs/ukia_20090012_en.pdf
- HM Government. (2009b). *Valuing people now: a new three-year strategy for people with learning disabilities. 'Making it happen for everyone'*. Retrieved from:
http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf
- Holland, A.J. (2000) Ageing and learning disability. *British Journal of Psychiatry* 176 pp 26-31.
<https://doi.org/10.1192/bjp.176.1.26>
- Howells, G. (1997). A general practice perspective. In J O'Hara & A. Sperlinger (Eds.), *Adults with Learning Disabilities: A Practical Approach for Health Professionals* (pp. 61–79). Chichester: John Wiley and Sons.
- Jones, S., Howard, L., & Thornicroft, G. (2008). 'Diagnostic overshadowing': worse physical health care for people with mental illness. *Acta Psychiatrica Scandinavica*, 118, 169-171.
doi:10.1111/j.1600-0447.2008.01211.x

- Jopp, D.A., & Keys, C.B. (2001). Diagnostic overshadowing reviewed and reconsidered. *American Journal on Mental Retardation*, 106, 416-433. doi:10.1352/0895-8017(2001)106<0416:DORAR>2.0.CO;2
- Kahneman, D. (2011). *Thinking, fast and slow*. London: Penguin Books.
- Kerr, M., Felce, D., & Felce, J. (2005). *Equal treatment: Closing the gap. Final report from the Welsh Centre for Learning Disabilities to the Disability Rights Commission*. Retrieved from: <http://disability-studies.leeds.ac.uk/files/library/kerr-Wales-learning-disability-study.pdf>
- Kwok, H., & Cheung, P. W. H. (2007). Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities. *Current Opinion in Psychiatry*, 20, 443-49. doi:10.1097/YCO.0b013e3282ab9941
- Lavis, D., Cullen, P., & Roy, A. (2009). Identification of hearing impairment in people with a learning disability: from questioning to testing. *British Journal of Learning Disabilities*, 25, 100-105. <https://doi.org/10.1111/j.1468-3156.1997.tb00020.x>
- Mason, J., & Scior, K. (2004). 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17, 85-90. <https://doi.org/10.1111/j.1360-2322.2004.00184.x>
- Mencap. (2004). *Treat me right! Better healthcare for people with a learning disability*. Retrieved from: https://www.mencap.org.uk/sites/default/files/2016-08/treat_me_right.pdf
- Mencap. (2007). *Death by indifference: Following up the Treat me right! report*. Retrieved from: <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>

Mencap. (2012) . *Death by indifference: 74 deaths and counting. A progress report 5 years on.*

Retrieved from: <https://www.mencap.org.uk/sites/default/files/2016->

[08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf)

Mencap. (2018a). *Treat me well.* Retrieved from:

<https://www.mencap.org.uk/sites/default/files/2018->

[02/Treat%20me%20well%20campaign%20report%20FINAL%20DIGITAL.pdf](https://www.mencap.org.uk/sites/default/files/2018-02/Treat%20me%20well%20campaign%20report%20FINAL%20DIGITAL.pdf)

Mencap. (2018b). *Mental health - research and statistics.* Retrieved from:

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/mental-health>

Michael, J. (2008). *Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities.* Retrieved from:

http://webarchive.nationalarchives.gov.uk/20130105064756/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care, Health and Development*, 35, 250–256. doi:10.1111/j.1365-2214.2008.00931.x

Morrow, K.A., & Deidan, C.T. (1992). Bias in the counselling process: how to recognise and avoid it. *Journal of Counseling and Development*, 70, 571-577.

<https://doi.org/10.1002/j.1556-6676.1992.tb01663.x>

Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 83-87.

doi:10.1111/j.1741-1130.2007.00104.x

- National Patient Safety Agency. (2004). *Understanding the patient safety issues for people with learning disabilities*. Retrieved from: <http://www.nrls.npsa.nhs.uk/resources/clinical-specialty/learning-disabilities/?entryid45=92328&p=2>
- Quirk, A., Chaplin, R., Lelliott, P., & Seale, C. (2011). How pressure is applied in shared decisions about antipsychotic medication: a conversation analytic study of psychiatric outpatient consultations. *Sociology of Health & Illness*, 34, 95-113.
<https://doi.org/10.1111/j.1467-9566.2011.01363.x>
- Reiss, S., Levitan, G.W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: diagnostic overshadowing. *American Journal of Mental Deficiency*, 86, 567-574.
Available from: <http://psycnet.apa.org/record/1982-25973-001>
- Reiss, S., & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally retarded persons. *American Journal of Mental Deficiency*, 87, 396-340.
Available from: <http://psycnet.apa.org/record/1983-10672-001>
- Royal College of Nursing. (2011). *Meeting the health needs of people with learning disabilities: RCN guidance for nursing staff*. Retrieved from: <https://www.rcn.org.uk/professional-development/publications/pub-003024>
- Royal College of Psychiatrists (2010). *No health without mental health: The supporting evidence*. Retrieved from: http://www.rcpsych.ac.uk/pdf/No%20Health%20-%20%20the%20evidence_%20revised%20May%202010.pdf
- Samele, C., Seymour, L., Morris, B., Central England People First, Cohen, A., & Emerson, E. (2006). *A formal investigation into health inequalities experienced by people with learning difficulties and people with mental health problems - Area Studies Report. Report to the Disability Rights Commission (DRC)*. Retrieved from:

<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/central-england-Area-Studies-Final-Report.pdf>

Schulman, K. A., Berlin, J. A., Hareless, W., Kerner, J. F., Sistrunk, S., Gersh, B. J., ... & Ayers, W. (1999). The effect of race and sex on physicians' recommendations for cardiac catheterisation. *The New England Journal of Medicine*, 340, 618–626.
doi:10.1056/NEJM199902253400806

Scior, K., & Werner, S. (2015). *Changing attitudes to learning disability: A review of the evidence*. Retrieved from: https://www.mencap.org.uk/sites/default/files/2016-08/Attitudes_Changing_Report.pdf

Scottish Government. (2017). *5 year survey of need for mental health inpatient care for children and young people in Scotland with learning disability and/or autism: Full report*. Retrieved from: <http://www.gov.scot/Resource/0052/00527514.pdf>

Secretary of State for Health. (2008). *Government Response to the Joint Committee on Human Rights: A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/243401/7378.pdf

SeeAbility. (2015). *An equal right to sight: why eye care for children with learning disabilities needs reform*. Retrieved from: <https://www.seeability.org/Handlers/Download.ashx?IDMF=0545bec4-912b-484a-95ce-67cb9a9986ed>

- Sowney, M., & Barr, O.G. (2006). Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing*, *55*, 36-45. doi:10.1111/j.1365-2648.2006.03881.x
- Spackman, R., Qureshi, A., Rai, D. (2016). A review of recommendations for medical undergraduate intellectual disability psychiatry teaching from UK reports. *Advances in Mental Health and Intellectual Disabilities*, *10*, 158-163.
<https://doi.org/10.1108/AMHID-03-2015-0014>
- Spengler, P. M., & Strohmer, D. C. (1994). Clinical judgmental biases: The moderating roles of counselor cognitive complexity and counselor client preferences. *Journal of Counseling Psychology*, *41*, 8-17. doi:10.1037/0022-0167.41.1.8
- Spengler, P.M., Strohmer, D.C., & Thompson Prout, H. (1990). Testing the robustness of the diagnostic overshadowing bias. *American Journal on Mental Retardation*, *95*, 204-214.
Available from: <http://psycnet.apa.org/record/1991-01654-001>
- Thomas, D., & Woods, H. (2003). Working with people with learning disabilities: Theory and practice. Retrieved from:
<https://books.google.co.uk/books?id=y6VqcpaZiEQC&pg=PA24&lpg=PA24&dq=difference+between+learning+disability+and+mental+illness&source=bl&ots=cFIcuaksxi&sig=I5MRj1XCdMKXFqrIPL9mQmuDZ1w&hl=en&sa=X&ved=0ahUKEwjZrMS-osPZAhWDLVAKHR71CeY4ChDoAQgnMAA#v=onepage&q=difference%20between%20learning%20disability%20and%20mental%20illness&f=false>
- Tuffrey-Wijne, I. (2002). The palliative care needs of people with intellectual disabilities: a case study. *International Journal of Palliative Nursing*, *8*, 222-232.
<https://doi.org/10.1191/0269216303pm668oa>

- Turner, S. (2011). *Health inequalities and people with learning disabilities in the UK: 2011. Implications and action for commissioners and providers of social care. Evidence into practice report no. 4*. Retrieved from:
https://www.ndti.org.uk/uploads/files/IHaL_2011_healthinequalitiessocialcare_guidance_final.pdf
- Tversky, A., & Kahneman, D. (1974). Judgement under uncertainty: heuristics and biases. *Science*, 185, 1124-1131. doi:10.1126/science.185.4157.1124
- While, A.E., & Clark, L.L. (2014). Development of a competency tool for adult trained nurses caring for people with intellectual disabilities. *Journal of Nursing Management* 22, 803–810. doi:10.1111/jonm.12002
- White, M. J., Nichols, C. N., Cook, R. S., Spengler, P. M., Walker, B. S., & Look, K. K. (1995). Diagnostic overshadowing and mental retardation: a meta-analysis. *American Journal on Mental Retardation*, 100, 293-298. Available from: <http://psycnet.apa.org/record/1996-14767-001>
- World Health Organisation (2001). *ICF: International classification of functioning, disability and health*. Geneva: World Health Organisation.
- Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). London: Sage.

SUZIE LEMMEY BSc (Hons) MSc

Section B:

**What can athletes with intellectual disabilities (ID)
tell us about taxonomic frameworks applied to ID?**

Word count = 7,964

Abstract

The International Classification of Functioning, Disability and Health (ICF) is a taxonomic framework that provides a biopsychosocial understanding of intellectual disabilities (ID). It was hypothesised that the use of the ICF would help highlight physical health difficulties in people with ID and promote a wider, more holistic view of ID. There was an additional practical aim concerning widening competing categories of athletes with ID to include physical health. The study consisted of two stages. In Stage one the ICF-based questionnaire was developed with an expert panel. Stage two aimed to test this using a naturalistic, cross-sectional design, between three pre-existing groups: elite athletes competing through INAS; sub-elite athletes; and athletes with Down syndrome (DS). Seventy-seven athletes took part. The results suggested that a separate competing category for athletes with DS should be considered, as this group could currently be considered disadvantaged in terms of their physical health when compared to INAS athletes. It was hoped this research would inspire further debate on a taxonomy for intellectual disabilities and the potential advantages of this, particularly in helping to ensure physical health problems in this population are not overlooked.

Keywords: Intellectual disabilities; taxonomy; athletes; ICF; health

1. Introduction

Intellectual disabilities (ID) have been associated with more physical health problems and higher morbidity compared to the general population (Emerson, Hatton, Baines, & Robertson, 2016). Concerns have been expressed through both research and policy in the UK that these health inequalities are exacerbated by factors such as diagnostic overshadowing. This occurs when a person's physical health problem is overlooked because of a more salient attribute, such as ID. It might be suggested that one way to address these inequalities would be to build upon current definitions and theories of ID so they encompass physical health more explicitly. This study built upon these ideas by developing a physical health questionnaire for people with ID (PWID), and piloting this with athletes with ID.

The British Psychological Society (BPS; 2015) define ID as a significant impairment in intellectual (IQ less than 70) and social (adaptive behaviour) functioning, with both beginning before 18-years of age. This definition is in line with classification frameworks such as the International Classification of Diseases (ICD; World Health Organisation (WHO), 1992). The pending ICD-11 (Salvador-Carulla et al., 2011) sub-classifies ID based on severity, whereas the BPS now only use 'severe', defined as three standard deviations below the mean on both measures of functioning.

Debate remains on the nature of ID and how this should be defined. Nakken and Vlaskamp (2007) highlighted the need for a taxonomy for ID. Fleishman and Quaintance (1984) define taxonomies as the "theoretical study of systematic classifications, including their bases, principles, procedures and rules" (p. 22). They describe the aim of taxonomy as describing how objects relate to each other, and organising these relationships into simple structures, or classes, so they can be spoken of as a coherent whole. Taxonomy gives a theoretical basis to

classification systems in a wide range of fields, including psychology, such as in personality (John, 1989), and education, such as Bloom's Taxonomy of the Cognitive Domain (as cited in Huitt, 2011, para. 1).

Nakken and Vlaskamp (2007), from the viewpoint of profound intellectual and multiple disabilities (PIMD), suggested a taxonomy for ID requires multiple classes, including physical disabilities. This was based on research showing increased physical health difficulties associated with decreasing IQ in PWID (Lahtinen, Rintala & Malin, 2007; Sweeney et al., 2016). However, physical health impairments are not solely an issue for people with severe ID. ID is associated with a greater prevalence of certain physical health conditions compared with the general population, including obesity, epilepsy, gastro-intestinal disorders, musculoskeletal problems and sensory impairments (Cooper et al, 2015, 2018; van Schrojenstein Lantman-De Valk, Metsemakers, Haveman, & Crebolder, 2000). Congenital heart disease occurs in over 60% of people with Down Syndrome (DS; Abbag 2006). DS is also associated with increased frequency of thyroid disorders, obesity, and poorer aerobic capacities, compared to PWID (Cooper et al, 2015; Baynard et al. 2004, 2008).

Few studies have specifically looked at multi-morbidity in PWID. Cooper et al. (2015) found that, compared with the general population, PWID in Scotland were significantly more likely to have one to four physical health problems. This finding was replicated in a smaller UK-wide study, which additionally found PWID were more likely to take five or more medications; these differences could not be fully explained by levels of deprivation (Emerson et al., 2016).

Problems with multiple morbidities have particularly been highlighted for people with PIMD (van Timmeren et al. 2016). These issues have been linked with sedentary lifestyles, obesity, and

increased use of medication, particularly antipsychotics, in this population (Cooper et al, 2015; Sweeney et al., 2016).

Reports such as ‘Death by indifference’ (Mencap, 2007; 2012) have consistently highlighted how health conditions are often not picked up in PWID, which can lead to premature death. Robertson, Roberts and Emerson (2010), in their systematic review of health check studies, found they resulted in “the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life-threatening conditions such as cancer, heart disease)” (p. 24). It is therefore important to give greater attention to the physical health of PWID, taking a more holistic perspective which considers both cognitive and physical issues. One means of achieving this would be to develop a wider taxonomy of ID that includes physical health.

The need for a wider taxonomy for ID has also been made following concerns regarding a perceived over-reliance on IQ scores, leading to people who need support being denied it (Webb & Whitaker, 2012; Wen, 1997). This project will therefore seek to develop and pilot a taxonomy of ID that includes physical health alongside IQ, with a view to providing a platform for future research that could examine the validity and utility of such a taxonomy for PWID more generally.

1.1 Athletes with ID

Athletes with ID have been chosen as a pilot case for this study for several reasons. Firstly, taxonomic theory is already used as the basis of Paralympic classification systems (Tweedy & Vanlandewijck, 2009). To be eligible to compete as a para-athlete with ID, athletes must have a diagnosis of ID (International Sports Federation for Persons with Intellectual Disability (INAS), 2016). At Paralympic level there is currently only one competing class for athletes with ID,

whereas multiple categories exist for physically disabled athletes; for example, swimming has 10 classes for physical impairment and three for visual impairment (International Paralympic Committee, n.d.).

There is burgeoning research suggesting that additional physical disabilities have been neglected in athletes with ID, and that this may be a larger predictor of athletic performance than IQ (Burns, 2015; Gilderthorp, 2015). This suggests some athletes with ID and additional disabilities are being excluded from competing at elite levels, as with one class they are competing against those without additional disability.

There is growing pressure to introduce additional classes for ID parasport to make it fairer to athletes with additional physical health problems. Tweedy (2002) cautioned against ignoring the process of taxonomic theory, which can lead to assumptions about what should be classified. It could be argued that neglect of this process led to recent scandals regarding classification of para-athletes (Grant, 2017; Walsh, 2017). It is therefore important to develop a reliable taxonomy to assess functional ability in athletes and stratify them into competing classes.

Additionally, there were practical reasons to work with athletes for this study. Targeting athletic events and clubs was a way of accessing a broader range of PWID, and therefore providing a more representative sample than in some past research (Turner, 2001). Athletes were already separated into three natural groups to provide comparisons: elite athletes, who competed with INAS; sub-elite athletes, who competed through local clubs and organisations such as the Special Olympics; and athletes with DS. Finally, it might be hypothesised that athletes with ID would be a relatively healthy population, and therefore a good test case for the sensitivity of a tool looking at physical health.

1.2 The International Classification of Functioning, Disability and Health (ICF; WHO, 2001)

One framework that could be drawn on to develop a taxonomy for PWID is the ICF (WHO, 2001). The ICF “is based on a theoretical model that represents the different domains of human functioning and their relationships” (Buntix & Schalock, 2010). This classification system aims to provide a holistic view of a person’s physical health, their ability to participate in activities, and contextual factors (environmental and personal) that may impact upon this and their general wellbeing. It includes a dimensional aspect, where different areas are rated in terms of difficulty. The ICF can therefore be viewed as a biopsychosocial model of disability (Barnes & Mercer, 2010).

Medical model-based classification systems, such as the ICD, have been critiqued as placing disability in the person and ignoring other factors, such as the environment. These models led the ‘Union of the Physically Impaired Against Segregation’ to develop the social model of disability to highlight how society is discriminatory (as cited in Barnes & Mercer, 2010, p. 30). However, this model has also been critiqued, particularly for not providing a theory of disability to allow research and validation to take place (Finkelstein, 2001). More recently, post-modernist and post-structuralist theories, often built on Foucault, have highlighted the importance of considering culture, language and dominant discourses in theories of disability (Barnes & Mercer, 2010). However, Shakespeare (2006) has critiqued these for providing little guidance for improving disabled people’s lives. He supported a critical realism perspective, and consequently the ICF as a classification system that both allowed meaningful research to be conducted, and incorporated the social model of disability through inclusion of environmental barriers.

The ICF is a comprehensively developed taxonomy, which was assessed for reliability and validity in trials in over 70 countries before its publication (Kostanjsek, 2011; WHO, 2001). It has been used extensively and internationally, in a wide variety of disciplines and with a wide variety of populations, including PWID (Jelsma, 2009; Maeda et al., 2005). Battaglia et al. (2004) found the ICF to have good applicability, reliability and criterion validity with children with cognitive, motor and complex disabilities.

As the ICF is already used as the basis of Paralympic classification systems, (Tweedy & Vanlandewijck, 2009) it was the logical choice for the basis of this study. Additionally, research groups have developed several ICF Core Sets for specific conditions, including Autism Spectrum Disorder (ASD; Bölte, Mahdi & Selb, 2016), and cerebral palsy in children and youth (Schiariti, Selb, Cieza, & O'Donnell, 2015). These are shortened versions of the ICF, which exclude categories that do not apply to these conditions, making them more practical for everyday use. These pre-existing sets were useful when deciding what would be important to include in a questionnaire.

To aid the use of the ICF in clinical practice, WHO developed the ICF Checklist (2003). This questionnaire consists of 125 categories covering all four sections of the ICF. It has been found to have good content, concurrent and discriminant validity, and acceptable internal consistency and inter-rater reliability (Aljunied & Frederickson, 2014; Kohler, Xu, Silva-Withmory & Arockiam, 2001). It also provided a good base for further research and a potential questionnaire template.

1.3 Summary and relevance to psychology

The ICF uses a functional definition of ID that provides a taxonomic framework for stepping away from deficit-based medical taxonomies such as the ICD. This wider, more holistic tool may reveal individual difference in PWID previously obscured by diagnostic frameworks. This research provided an opportunity to explore the taxonomy of ID in the context of athletes with ID. Testing the ICF in this population, where co-morbidity was likely to be less than the general ID population, allowed for a good test of the sensitivity of the method between three groups with hypothesised differences in their physical health. This study also adds to the emerging literature about the extent of unrecognised health problems in PWID, even within a hypothesised ‘healthy’ ID population.

This project has clinical relevance, as use of the ICF could reduce the impact of medical labels on PWID, such as stigma and social exclusion (Thomas & Woods, 2003). Widening the definition of ID is something psychologists should be, and are, involved with (Webb & Whitaker, 2012). This also relates to issues of diagnostic overshadowing in PWID; this will be considered further in the Discussion.

This project also aimed to widen access to elite sport to all PWID, including those with physical health problems. Involvement in sport has been found to have benefits for PWID, in terms of improved fitness (Hutzler & Korsensky, 2010) and motor abilities (Orellove, Wehman & Wood, 1982). It is also a driver for social inclusion (Sweeney et al., 2016), which has been recognised by the BPS as an important psychological aim (2008).

1.4 Research question and hypotheses

Question:

- a. What do a panel of experts think are the factors within the ICF (body functions section) that apply to athletes with ID?

Hypotheses:

- b. The 'ICF-based questionnaire' will be shown to be a reliable and valid measure.
- c. The ICF-based questionnaire will discriminate between three groups of athletes with ID who have different levels of physical/sensory disabilities, i.e.:
 1. elite athletes with INAS (hypothesised to be unrepresentative of athletes with ID due to a low level of additional physical disabilities; Gilderthorp, 2015)
 2. sub-elite athletes (hypothesised to have more additional physical disabilities than elite athletes, but fewer than those with Down Syndrome; Gilderthorp, 2015)
 3. athletes with Down's Syndrome (DS) (hypothesised to have the greatest level of additional physical and sensory disabilities: Arevalo, 2001; Cooper et al, 2015; Sweeney et al., 2016; Turner, 2001).
- d. Following on from c, the ICF-based questionnaire, will continue to evidence additional difficulties in groups 2 and 3 relative to group 1, even when IQ is controlled for.
- e. As IQ scores decrease, the overall ICF-based questionnaire score (i.e. the total number of additional disabilities) will increase. This was based on research linking decreasing IQ with increased physical health difficulties (Lahtinen et al., 2007; Sweeney et al., 2016) and higher mortality rates (Patja et al., 2000).

2. Method

2.1 Design

The study consisted of two stages. Stage one focussed on developing a questionnaire based on the ICF. Experts were consulted to identify applicable items from the ICF. Stage two aimed to test the ICF-based questionnaire using a naturalistic, cross-sectional, between group design. This was done with three pre-existing groups: elite athletes who competed through INAS; sub-elite athletes; and athletes with DS.

2.2 Participants

2.2.1 Stage 1: Expert panel. The inclusion criteria for the expert panel were: experience of being, caring for or working with PWID (preferably athletes); good spoken and written English; and that the three groups were represented. Thirteen people were approached via email to complete the questionnaire, and eleven responded (Table 1). These were people known through INAS, the Special Olympics and research networks.

2.2.2 Stage 2: Empirical study. Inclusion criteria for the athletes are shown in Table 2. All athletes had to: have an ID diagnosis; be 18-years of age or older; and be able to provide informed consent. They also needed to be accompanied by someone who knew them well and who spoke English, enabling them to act as a translator, if needed.

Overall, 91 athletes agreed to take part in the study. Fourteen athletes were excluded: three who were under 18; seven who scored above 75 on the WASI-II; one when it became apparent they did not have ID (they were at university); one who did not complete the interview as they were upset about losing their match; and two who completed the WASI-II but did not respond to follow-up. This gave a sample size of 77. Details on the demographics of the athletes are

included in Table 7 in the Results section. The majority of interviews took place face-to-face, with eight INAS athletes interviewed over Skype or Facetime.

Table 1
Details of the expert panel

<u>Job title</u>	<u>Experience</u>	<u>Gender</u>	<u>Nationality</u>
Carer representative	Mother of an INAS (The International Association of Sport for para-athletes with ID) athlete	Female	Australian
INAS Athlete representative	Swimmer. Registered with INAS since 2011.	Female	Australian
Commissioning Manager – Learning Disabilities	Council member with responsibilities for PWID. Also a supporter of ID athletes.	Male	British
PhD student	Working in health and ID. Involved with the Special Olympics.	Male	British
Lead researcher	Working in intellectual disability and sport.	Female	Belgian
Researcher	Working in intellectual disability and sport.	Female	Belgian
Member of INAS	Coach of athletes with ID	Male	American
Member of INAS	Involved with sport for PWID at a National and International level for over 20 years	Female	Australian
Researcher in sport, health and ID	And Coach with athletes with ID	Male	Icelandic
Psychiatrist	Working in eligibility for athletes with ID	Female	French
Consultant Clinical Psychologist	Specialist in Intellectual Disabilities	Male	British

The DS group consisted of 23 athletes with trisomy 21 (72%), one athlete with mosaicism (3%) and one with translocation (3%). Information on the type of DS was unknown for seven (22%).

Table 2

Inclusion criteria for the three different groups of athletes with ID

<u>Inclusion criteria</u>	<u>Group</u>		
	<u>INAS</u>	<u>Sub-elite</u>	<u>DS</u>
ID diagnosis, including standardised measure of Full Scale IQ of 75 or below (in line with the INAS Eligibility & Classification criteria (2016))	✓	✓	✓
Participated in a sport event in the past 12 months	✓ INAS event	✓ Regional- level event	✓
Accompanied by an English-speaking supporter familiar with them and their medical history	✓	✓	✓
18+ years old	✓	✓	✓
Able to provide informed consent	✓	✓	✓
DS diagnosis (as reported by athlete and supporter)	X	X	✓

2.3 Ethics

Full approval was received from a University Ethics Panel in October 2016 (Appendix B).

Consideration was given to the potential for athletes to become distressed, if the questions were experienced as too personal, or due to issues around competing at their sporting event. Following research on obtaining informed consent to participate in research with PWID, the athlete's consent to participate was re-evaluated at various points in the interview (Cameron & Murphy, 2006). This helped to ensure participants were aware they did not have to answer all questions, and they could take a break or terminate the interview at any time. To help ensure participating

athletes could understand the study and what was involved an 'Expert by Experience', who had a diagnosis of ID, was consulted to tailor the language used in the information sheet and consent forms (Appendix C & D). For the INAS group, the consent form also gave agreement to the release of information about their IQ, held by INAS as part of their eligibility application (Appendix E).

2.4 Materials/Measures

2.4.1 Qualtrics questionnaires (research question a). To gather feedback from the expert panel, an online questionnaire was developed using Qualtrics (version January 2017; Appendix F). The 114 Body Functions categories in the ICF were reviewed and reduced to the 31 the research literature suggested would be most relevant for PWID (Table 3). This excluded categories under: voice and speech functions; genitourinary and reproductive functions; functions of the skin and related structures; and mental functions, as these tended to either be irrelevant to physical health (such as emotional functions) or already covered by a diagnosis of ID (such as intellectual functions). It also excluded categories under functions of the digestive, metabolic and endocrine systems. The panel were invited to comment on additional areas of physical health they felt had been missed off the questionnaire.

2.4.2 ICF-based questionnaire (hypotheses b to e). The ICF consists of over 1,400 categories under four components: body functions; body structures; activities and participation; and environmental factors. These categories can then, as in the ICF Checklist (WHO, 2003), be used as questionnaire items to categorise conditions in relation to this taxonomy. The developed ICF-based questionnaire used categories under body functions only to keep the focus on physical health and functional ability.

On consulting the literature, and with a researcher who had used the ICF with PWID (Faulks, 2017, personal communication), the wording of the questions was adapted from the ICF to use simpler language. Additional guidance was provided on common problems and providing more detailed explanations (Table 4; Appendix G). If the athlete answered ‘Yes’ to the first part of a question they were asked a second question to gauge the extent of the problem, using a scale adapted from the ICF Checklist (WHO, 2003; Appendix H). ‘No problem’ was scored as zero, going up to a score of four for ‘Complete problem’, giving a possible range of scores across the whole questionnaire of between zero and 140. The ICF-based questionnaire also included questions to gather demographic information and information on current health, using the ICF Checklist as a template (Appendix G).

Table 3

Common physical health problems to be covered for people with ID and people with DS in the ICF-based questionnaire, as based on common themes in the research literature

<u>Physical health condition</u>	<u>References for People with LD</u>	<u>References for people with DS</u>
Arthritis / joint problems	Cooper et al., 2015; Emerson et al., 2016; Howells, 1997	-
Congenital heart disease	-	Abbag 2006; Howells, 1997; Turner, 2001
Musculoskeletal difficulties	-	Arevalo, 2001; Howells, 1997; Turner, 2001
Respiratory problems, including asthma	Cooper et al. 2015; 2018; Emerson et al., 2016; Howells, 1997; Sperlinger, 1997	-
Sensory impairments	Cooper et al., 2015; Sperlinger, 1997; Turner, 2001; van Schroyen Lantman-De Valk et al., 2000; van Timmeren et al., 2016	Cooper et al., 2015; Howells, 1997; Turner, 2001

Table 4

Examples of changes in wording between the ICF (WHO, 2001) and the ICF-based questionnaire

Wording in ICF	Wording in ICF-based questionnaire*
<p>b 210 Seeing functions Sensory functions relating to sensing the presence of light and sensing the form, size, shape and colour of the visual stimuli.</p> <p>Inclusions: visual acuity functions; visual field functions; quality of vision; functions of sensing light and colour, visual acuity of distant and near vision, monocular and binocular vision; visual picture quality; impairments such as myopia, hypermetropia, astigmatism, hemianopia, colour-blindness, tunnel vision, central and peripheral scotoma, diplopia, night blindness and impaired adaptability to light Exclusion: perceptual functions (b156)</p>	<p><i>Please answer this question for how you see without glasses, if you wear them</i></p> <p>Q3a. Do you have problems with seeing things?</p> <p>[Problems with sensing the presence of light and/or seeing form, size, shape and colour. Including: impairments such as myopia (short-sightedness), hypermetropia (long-sightedness), astigmatism, hemianopia (blindness over half the field of vision), colour-blindness, tunnel vision, central and peripheral scotoma (a partial loss of vision or blind spot in an otherwise normal visual field), diplopia (double vision), night blindness and impaired adaptability to light]</p>
<p>b 410 Heart functions Functions of pumping the blood in adequate or required amounts and pressure throughout the body.</p> <p>Inclusions: functions of heart rate, rhythm and output; contraction force of ventricular muscles; functions of heart valves; pumping the blood through the pulmonary circuit; dynamics of circulation to the heart; impairments such as tachycardia, bradycardia and irregular heart beat and as in heart failure, cardiomyopathy, myocarditis, and coronary insufficiency Exclusions: blood vessel functions (b415); blood pressure functions (b420); exercise tolerance functions (b455)</p>	<p>Q13a. Do you have problems with your heart?</p> <p>[Problems with the heart pumping blood around the body. Including: problems with heart rate and rhythm; the heart muscles; the heart valves; impairments such as tachycardia (abnormally high heart rate), bradycardia (abnormally slow heart rate) and irregular heart beat and as in heart failure, cardiomyopathy (chronic disease of the heart muscle), myocarditis (inflammation and damage of the heart muscle) and coronary insufficiency (insufficient blood flow through one or more arteries in the heart)]</p>
<p>b 710 Mobility of joint functions Functions of the range and ease of movement of a joint.</p> <p>Inclusions: functions of mobility of single or several joints, vertebral, shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet; mobility of joints generalized; impairments such as in hypermobility of joints, frozen joints, frozen shoulder, arthritis Exclusions: stability of joint functions (b715); control of voluntary movement functions (b760)</p>	<p>Q23a. Do you have problems with moving your joints?</p> <p>This includes problems such as in hypermobility of joints (like your wrist moving back too far), frozen joints, and arthritis</p> <p>[This means problems with the range and ease of movement of a joint. This includes: problems with the mobility of a single or several joints; mobility of joints in general. joints include: vertebral (spine), shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet]</p>

* Information provided in square brackets was to provide more information if requested and to highlight common problems in these areas, along with their meaning, to researchers.

2.4.3 WASI-II (hypotheses c and e). The reliability and validity of the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II) are considered high and comparable with other IQ measures (Wechsler, 2011). There is “Strong evidence” for the use of this measure of IQ with PWID (Wechsler, 2011, p. 139). The BPS have suggested its usefulness as a screening measure (2015).

The two-subtest version was used in this study. This consists of the Vocabulary and Matrix Reasoning subtests, providing a Full-Scale IQ (FSIQ), where the average score is 100. Following the INAS eligibility criteria (INAS, 2016) the cut-off for intellectual disability was set at 75.

2.4.4 Other measures of IQ (hypotheses c and e). INAS athletes had already provided evidence of their IQ scores and had these verified by the INAS Eligibility Panel, which involves independent scrutiny by two experienced psychologists. These were primarily Weschler scales normed for use in the athlete’s country (Table 5). The BPS consider the WAIS and the WISC to be valid and reliable measures, and thus the ‘gold standard’ for contributing to diagnosis of intellectual disabilities in adults and children respectively (2015; Webb & Whitaker, 2012). For one athlete the Stanford Binet-5 was used as an assessment of IQ. This assessment, like the WAIS and WISC, has been deemed to be a reliable and valid tool for the purposes of para-athlete eligibility (INAS, 2016).

2.4.5 Post-questionnaire interview (hypotheses b). To evaluate the ICF-based questionnaire, a short post-questionnaire interview schedule was produced (Appendix I). This included direct questions to establish whether the athlete had a diagnosis of ASD, epilepsy or cerebral palsy. Responses could then be cross-referenced with items in the ICF-based questionnaire to establish whether these areas had been adequately captured. These areas were chosen as the expert panel, and later athletes completing the questionnaire, highlighted them as

important to be covered. Open-ended questions were also included to evaluate how the athlete experienced the questionnaire, to ensure it was suitable for use as a measure of eligibility with PWID.

Table 5
Measures of IQ reported for the INAS group

<u>Measure of IQ</u>	<u>Editions</u>
Wechsler Adult Intelligence Scale – Third Edition (WAIS-III) (Wechsler, 1997)	Australian, Chinese, German, Netherlands and UK
Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV) (Wechsler, 2010)	French, Netherlands, UK and US
Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV) (Wechsler, 2003)	Australian, Chinese, Hong Kong and UK
Stanford Binet	5

2.5 Procedure

2.5.1 Stage 1: Expert panel. This procedure was based on the initial stages used to develop ICF Core Sets (Selb et al, 2015). The expert panel were emailed the Qualtrics questionnaire and asked to rate the commonality of each problem area from zero (very rare) to 100 (very common). This allowed each item to be checked across the panel for reliability (a small range in responses) and content validity. To get a measure of their confidence in their responses, they were then asked how easy they found it to answer each question, from one (extremely easy) to five (extremely difficult) (Appendix F).

Following analysis of the findings (see Results), the questionnaire was reviewed and sent back to the Expert Panel for further comment. The final version of the ICF-based questionnaire was produced with the help of an Expert by Experience (Appendix G). This involved a pilot interview and discussions on the wording.

Versions of the ICF-based questionnaire were created in German, French, Spanish and Finnish using the WHO online tool (<http://www.icf-core-sets.org/en/page0.php>). Whilst these used the original ICF language, they proved to be a useful reference for athletes and their supporters to check any English medical terms they did not recognise. Further minor revisions were made in the early stages of data collection following feedback from interviews, involving changing some wording and increasing the questionnaire to 35 items. For example, control of voluntary movement was broken down further to include fine motor skills.

2.5.2 Stage 2. Empirical study. Representatives at INAS, the Special Olympics and Mencap were approached via email for permission to attend events. Permission to attend specific events was then sought via email through the local organiser. Event organisers were sent details on the research and what would be required (Appendix J). They were asked to display the relevant information sheets on their event registration page and, if possible, forward these to coaches. If athletes were interested in taking part, or wanted to ask questions before deciding, there were able to contact the researcher in advance of the event through details supplied on the information sheet. The same method was later used to contact sports clubs.

Seven sporting events were attended, including a European event in the Czech Republic and an international event in the UK. In addition, eight clubs and training events were visited in England and France. Coaches, parents and athletes were approached at the events and given information sheets. If they were interested in taking part a suitable time to meet was arranged. The athletes and their supporters were met in a private space. After reviewing the information sheet, answering any questions about the research and seeking consent, the athletes were verbally administered the ICF-based questionnaire, followed by the post-interview questionnaire. Non-

INAS athletes were also asked to complete the WASI-II, which they could choose to complete before or after the ICF-based questionnaire, according to their preference.

The opportunity to conduct all or part of the interview via Skype or Facetime was offered (the WASI-II was always conducted face-to-face). INAS athletes and coaches were invited to take part solely over Skype via advertisements on the INAS website and in their newsletter.

For large events in the UK, additional researchers were recruited through local Assistant Psychologist organisations and word-of-mouth. They were asked to sign a confidentiality statement (Appendix K). Further materials and training on completing the interviews was provided (Appendix L). Additional researchers only completed the WASI-II if they had sufficient experience of completing neuropsychological assessments and of working with PWID.

2.6 Data Analysis

Data analysis was conducted using SPSS statistical analysis software, version 23 (IBM Corp, 2015). Additional effect sizes were calculated using formulas in Field (2013). The analyses that were undertaken at each stage and to address each hypothesis are outlined below.

2.6.1 Stage 1. The results from the expert group were analysed using descriptive statistics.

2.6.2 Stage 2. An initial analysis was conducted on the demographic data to check for differences between the three groups. For the categorical variables (gender; health problems; medication; assistive devices) a Pearson Chi-Square was used. For the others (age; years competing) a one-way independent analysis of variance (ANOVA) was used. Where significant results were found, post-hoc pairwise comparisons were conducted to look for differences between the groups. Given the number of potential comparisons, the Bonferroni adjustment was

chosen to control for Type 1 errors. Following Clark-Carter (2010), the p -values are reported alongside the Bonferroni-adjusted significance threshold.

2.6.3 Hypothesis B. The reliability of the ICF-based questionnaire was analysed using Cronbach's alpha. To check for criterion validity, responses to items in the post-interview questionnaire (on ASD, epilepsy and cerebral palsy) were cross-checked with items in the ICF-based questionnaire that corresponded with the ICF-core sets for ASD (Bölte et al., 2016) and cerebral palsy (Schariti, et al., 2015), and a ICF-based research paper on epilepsy (Cerniauskaite et al., 2012). As the data for the ICF-based questionnaire items were non-normally distributed, and responses to the post-interview questions were categorical, the Mann-Whitney test was used.

In addition, Stage 1 assessed the content validity of the ICF-based questionnaire, and hypothesis E assessed for convergent validity with IQ.

2.6.4 Hypothesis C. The ICF scores were treated as ordinal data, as the difference between the values may not have been equal (for example a 'complete' problem, scored 4, was not necessarily double a 'moderate' problem, scored 2). Due to this, and the positive skew to the ICF scores, the non-parametric Kruskal-Wallis test was used to analyse the ICF scores by group. Pairwise comparisons would be conducted on the data if the Kruskal-Wallis test showed a significant omnibus effect, to identify what group difference(s) were driving this. Following Field (2013), Bonferroni-adjusted p -values were reported. The ICF scores between groups were illustrated with a boxplot and histograms.

2.6.5 Hypothesis D. To establish whether there was a difference in IQ between the groups, and therefore whether it should be controlled for, a one-way between participants ANOVA was conducted. Due to the differences in sample sizes, post-hoc comparisons were conducted using Gabriel's procedure (Field, 2013). A multinomial logistic regression was then conducted, with

groups as the outcome variable. A power calculation was conducted to determine the necessary sample size, giving a target of 31 athletes in each of the three groups (Field, 2013; $N=92$). This was calculated using a medium effect size and five predictors (IQ, ICF-based questionnaire score, age, gender, and number of years competing). To more directly test the hypothesis, another multinomial logistic regression was conducted using just IQ and ICF score as variables.

2.6.6 Hypothesis E. The non-parametric Spearman one-way correlation was used to measure the association between ICF score and IQ. A scatterplot was used to illustrate the results.

3. Results

3.1 Stage 1: What do a panel of experts think are the body functions within the ICF that apply to athletes with ID?

The panel rated how commonly they thought each problem occurred in PWID, from 0 (very rare) to 100 (very common; Table 6). They reported the lowest as, “Problems relating to sensing temperature and other stimuli” ($M = 14.00$, $SD = 8.72$), and the highest as, “Problems with joint mobility” ($M = 43.50$, $SD = 33.69$). The panel judged all items to be common to more than 10% of PWID. None of the mean results suggested these questions were difficult to answer, which gave further support for the applicability of the questions to PWID. As the experts expressed a range of views about which items were important, an inclusive approach was taken to maximise the chances of the measure being comprehensive. Consequently, all the items were included in the questionnaire.

The panel’s responses resulted in questions being included in the questionnaire under three categories: senses and pain; the heart, lungs and immune system; and movement and mobility.

Following comments from the panel and the Expert by Experience, a further three questions were added to cover issues with obesity and epilepsy. This included energy and drive (b130), weight maintenance (b530), and consciousness (b110), taken from the ICF Core Set on Obesity (Stucki et al., 2004) and research on epilepsy using the ICF (Cerniauskaite et al., 2012). An additional item to help capture ASD (b122: global psychosocial function) was suggested by the expert panel but removed following consultation with the Expert by Experience, as the question was felt to be overcomplicated.

Table 6
*Results from the expert panel to the first draft of the ICF-based questionnaire**

<u>Qu No.</u>	<u>Question</u>	<u>N</u>	<u>M</u>	<u>Mdn</u>	<u>SD</u>	<u>Min-Max</u>	<u>Range</u>
SENSES AND PAIN							
1a	Problems with seeing	10	28.0	22.5	20.6	8 - 70	62
1b	How easy?	10	2.7	2.5	1.3	1 - 4	3
2a	Problems with structures adjoining the eye	10	17.9	15.0	13.9	2 - 40	38
2b	How easy?	10	3.6	4.0	1.4	1 - 5	4
3a	Problems associated with the eye and adjoining structures	10	15.2	13.5	13.1	0 - 40	40
3b	How easy?	10	3.3	3.5	1.2	1 - 5	4
4a	Problems with hearing	10	26.4	25.5	21.2	5 - 81	76
4b	How easy?	9	2.7	3.0	1.2	1 - 4	3
5a	Problems with the vestibular system	9	23.3	20.0	24.9	3 - 85	82
5b	How easy?	9	3.0	3.0	1.6	1-5	4
6a	Problems associated with hearing and vestibular function	9	14.6	15.0	10.3	3 - 30	27
6b	How easy?	9	3.3	4.0	1.2	1 - 5	4
7a	Problems with proprioceptive function	10	30.6	27.5	23.7	3 - 65	62
7b	How easy?	10	2.7	2.5	1.1	1 - 4	3
8a	Problems related to touch	9	19.1	20.0	14.1	3 - 40	37
8b	How easy?	10	2.7	2.5	1.3	1 - 4	3
9a	Problems related to sensing temperature and other stimuli	8	14.0	12.5	8.7	3 - 29	26
9b	How easy?	10	3.0	3.0	1.1	1 - 4	3
10a	Sensations of pain	10	27.6	22.5	24.1	3 - 78	75
10b	How easy?	10	2.8	3.0	1.0	1 - 4	3
THE HEART, LUNGS AND IMMUNE SYSTEM							
11a	Problems with the heart	10	25.2	30.0	18.4	0 - 50	50
11b	How easy?	10	3.4	4.0	1.2	1 - 5	4

12a	Problems with blood vessels	9	18.6	10.0	16.7	0 – 50	50
12b	How easy?	10	3.5	4.0	1.0	1 - 4	3
13a	Problems with blood pressure	9	27.0	10.0	30.0	0 – 80	80
13b	How easy?	10	3.3	3.5	1.0	1 - 4	3
14a	Problems with the immune system	10	22.6	20.5	15.7	0 – 51	51
14b	How easy?	10	3.3	3.5	1.0	1 - 4	3
15a	Problems with respiration	10	28.8	27.5	23.3	0 – 70	70
15b	How easy?	10	3.0	3.0	1.1	1 - 4	3
16a	Problems with the respiratory muscles	10	14.4	14.5	11.6	0 – 30	30
16b	How easy?	10	3.3	4.0	1.4	1 - 5	4
17a	Additional respiratory issues	10	15.8	14.0	12.4	0 – 40	40
17b	How easy?	10	3.3	3.5	1.2	1 - 5	4
18a	Exercise tolerance	10	43.1	33.5	38.9	0 – 92	92
18b	How easy?	10	2.3	2.0	0.9	1 - 4	3
19a	Sensations associated with cardiovascular and respiratory functions	10	20.9	11.5	21.8	0 – 69	69
19b	How easy?	10	3.000	3.500	1.1	1 - 4	3
MOVEMENT AND MOBILITY							
20a	Problems with joint mobility	10	43.5	36.0	33.7	0 – 90	90
20b	How easy?	10	2.1	2.0	0.7	1 - 3	2
21a	Problems with the stability of joints	10	24.9	16.0	24.1	0 – 68	68
21b	How easy?	10	2.7	3.0	1.2	1 - 4	3
22a	Problems with the mobility of bones	9	15.3	11.0	11.5	0 – 31	31
22b	How easy?	10	3.1	3.0	1.2	1 - 5	4
23a	Problems with muscle power	10	38.9	34.5	30.5	0 – 91	91
23b	How easy?	10	2.1	2.0	0.6	1 - 3	2
24a	Problems with muscle tone	10	37.2	30.0	31.1	0 – 87	87
24b	How easy?	10	2.3	2.0	0.8	1 - 4	3
25a	Problems with muscle endurance	10	30.1	30.0	28.7	0-84	84
25b	How easy?	10	2.9	3.0	1.0	1 - 4	3
26a	Problems related to motor reflexes	9	28.0	30.0	22.8	0 – 71	71
26b	How easy?	10	2.9	3.0	1.1	1 - 4	3
27a	Problems related to involuntary movement reactions	10	20.5	20.0	15.1	0 – 52	52
27b	How easy?	10	2.8	3.0	0.9	1 - 4	3
28a	Problems related to control of voluntary movement	10	34.8	33.0	31.1	0 – 85	85
28b	How easy?	9	2.7	3.0	0.9	1 - 4	3
29a	Problems related to involuntary movement	10	24.9	28.5	18.3	0 – 64	64
29b	How easy?	10	3.0	3.0	1.2	1 - 5	4
30a	Problems related to gait pattern	10	23.8	26.0	16.3	0 – 54	54
30b	How easy?	10	2.4	2.0	0.8	1 - 4	3
31a	Sensations related to muscles and movement functions	10	23.3	15.5	22.8	0 – 76	76
31b	How easy?	10	3.1	3.0	1.0	1 - 4	3

*Questions on physical health problems were rated on a scale from 0 (very rare) to 100 (very common). The 'How easy?' question was answered on a scale of 1 (extremely easy) to (extremely difficult).

Table 7
Characteristics of participating athletes

		Athlete group (N = 77)		
		INAS	Sub-elite	DS
		(n = 26)	(n = 19)	(n = 32)
Gender	Female (%)	9 (34.6)	10 (52.6)	10 (31.3)
	Male (%)	17 (65.4)	9 (47.4)	22 (68.7)
Nationalities	American (%)	3 (11.5)	0	0
	Australian (%)	5 (19.2)	2 (10.5)	1 (3.1)
	Belgian (%)	2 (7.7)	0	0
	British (%)	7 (26.9)	16 (84.2)	25 (78.1)
	British/Caribbean (%)	1 (3.8)	0	0
	British/Indian (%)	0	1 (5.3)	0
	British mixed (%)	0	0	2 (6.3)
	Chinese (%)	3 (11.5)	0	0
	Czech (%)	1 (3.8)	0	0
	French (%)	3 (11.5)	0	4 (12.5)
	German (%)	1 (3.8)	0	0
Ethnicity	Black British (%)	0	1 (5.3)	0
	Black British/Caribbean (%)	1 (3.8)	2 (10.5)	0
	British/Indian (%)	0	1 (5.3)	0
	Chinese (%)	4 (15.4)	0	0
	White Australian (%)	0	2 (10.5)	1 (3.1)
	White British (%)	6 (23.1)	11 (57.9)	24 (75.0)
	White European (%)	7 (26.9)	0	5 (15.6)
	White Irish (%)	0	1 (5.3)	0
	White Other (%)	6 (23.1)	0	1 (3.1)
	Mixed (%)	2 (7.7)	1 (5.3)	1 (3.1)
Competing sport	Athletics (%)	8 (30.8)	4 (21.1)	0
	Basketball (%)	0	3 (15.8)	0
	Boccia (%)	0	1 (5.3)	1 (3.1)
	Cricket (%)	0	3 (15.8)	0
	Cycling (%)	1 (3.8)	0	0
	Equestrian (%)	0	2 (10.5)	0
	Football (%)	0	0	1 (3.1)
	Netball (%)	0	2 (10.5)	1 (3.1)
	Power lifting (%)	0	1 (5.3)	0
	Swimming (%)	4 (15.4)	2 (10.5)	27 (84.4)
	Table tennis (%)	4 (15.4)	1 (5.3)	0
	Tennis (%)	9 (34.6)	0	0
	Ten pin bowling (%)	0	0	2 (6.3)
Diagnosed with epilepsy (%)		2 (7.7)	2 (10.5)	0
Diagnosed with ASD (%)		11 (42.3)	6 (31.6)	2 (6.3)
Diagnosed with Cerebral Palsy (%)		2 (7.7)	0	0

3.2 Stage 2

All athletes completed the full ICF-based questionnaire and post-interview questionnaire. IQ information was missing for two of the sub-elite athletes and for four of the DS athletes. For all results, unless stated otherwise, statistical significance was set at $p < .05$.

There was no significant difference in gender balance across the three groups, $\chi^2(2, N = 77) = 2.48, p = .290$ (Table 7). Although the sub-elite athletes had a higher mean age (Table 8), the differences between the age of the INAS, sub-elite and DS groups only approached significance ($p = .053$). There were no significant differences across groups for the number of years competing, either in the sport they were currently competing in, or years competing overall. This suggested the three groups were similar on these variables.

Table 8
Characteristics of participating athletes: age and years competing

	Athlete group ($N = 77$)			$F(2, 74)$	r
	INAS ($n = 26$)	Sub-elite ($n = 19$)	DS ($n = 32$)		
	$M (SD)$	$M (SD)$	$M (SD)$		
Age	25.42 (8.03)	31.68 (9.45)	26.66 (8.86)	3.06	0.28
Years competing in this sport	11.81 (7.75)	14.11 (9.07)	9.75 (6.79)	1.93	0.22
Years competing in any sport	12.38 (8.34)	14.11 (9.07)	10.53 (6.75)	1.25	0.18

* $p < .05$

Table 9 shows the analysis of each group for the remaining demographic questions. The use of assistive devices significantly differed across the groups. There was also a significant relationship between the groups and whether the device could be worn during sport. Post-hoc comparisons (Table 10) found significant results on these variables between the INAS and DS groups only. This might partly be explained by the greater number of swimmers in the DS group

(Table 7); although some swimmers had prescription goggles, this was not true for all, and it was often not possible to wear other assistive devices in this sport.

Table 9

Comparing the groups on use of assistive devices, and current health and medication use

		Athlete group (N = 77)			χ^2 (df)
		<u>INAS</u> (n = 26)	<u>Sub-elite</u> (n = 19)	<u>DS</u> (n = 32)	
Do you use any assistive devices?*	Yes (%)	11 (42.3)	14 (73.7)	27 (84.4)	12.01** (2)
	Glasses (%)	10 (90.9)	13 (92.9)	25 (92.6)	-
	Hearing aid (%)	2 (18.2)	3 (21.4)	4 (14.8)	-
	Orthotics (%)	1 (9.1)	0	4 (14.8)	-
Can you wear them during sport?	No (%)	4 (36.4)	3 (21.4)	16 (59.3)	16.10* (6)
Do you have any problems with your health at the moment?	Yes (%)	9 (34.6)	14 (73.7)	18 (56.3)	6.93* (2)
	Asthma/ breathing problems (%)	2 (7.7)	5 (26.3)	3 (9.4)	-
	Constipation (%)	0	1 (5.3)	2 (6.3)	-
	Diabetes (%)	1 (3.8)	2 (10.5)	0	-
	Epilepsy (%)	1 (3.8)	2 (10.5)	0	-
	Gastrointestinal issues (%)	2 (7.7)	1 (5.3)	0	-
	Headaches (%)	2 (7.7)	0	1 (3.1)	-
	Heart problems (%)	2 (7.7)	0	0	-
	High blood pressure (%)	1 (3.8)	2 (10.5)	0	-
	Injury (%)	1 (3.8)	2 (10.5)	0	-
Thyroid problems (%)	0	1 (5.3)	11 (34.4)	-	
Are you taking any medication?	Yes (%)	9 (34.6)	13 (68.4)	20 (62.5)	6.46* (2)

*Percentages for assistive devices equal more than 100 as an athlete could have more than one.

** $p < .05$ *** $p < .01$

The most commonly reported physical health problems are included in Table 9. Current health significantly differed across the groups. The association between taking medication and group

was also significant. Post-hoc comparisons (Table 10) found significant results between the INAS and sub-elite group for health only.

Table 10

Post-hoc comparisons between the three groups on use of assistive devices, and current health and medication use

	INAS v Sub-elite		INAS v DS		Sub-elite v DS	
	χ^2	<i>p</i>	χ^2	<i>p</i>	χ^2	<i>p</i>
Do you use any assistive devices?	4.38	.036	11.24	.001*	0.86	.353
Can you wear them during sport?	2.06	.358	11.51	.009*	7.11	.068
Do you have any problems with your health at the moment?	6.71	.010*	2.69	.100	1.55	.213
Are you taking any medication?	5.02	.025	4.46	.035	0.18	.669

* Significant at Bonferroni-adjusted alpha level of .017

3.3 Hypothesis B: The ICF-based questionnaire will be shown to be a reliable and valid measure

Using all 35 problem-related items on the ICF-based questionnaire gave an acceptable internal consistency, Cronbach's $\alpha = .75$ (Field, 2013). This suggested the questionnaire was sufficiently internally consistent, and a sum of all the individual item scores (the 'ICF score') could be used in the analysis.

In the full sample, only two athletes responded 'Yes' to the question in the post-interview questionnaire asking if they had a diagnosis of cerebral palsy, and only four to the question on epilepsy. The planned analyses on these questions was therefore not completed.

Table 11 shows no significant differences between the additional question on ASD and the three items on the ICF-based questionnaire also present in the ICF Core Set for ASD (Bölte et

al., 2016). This suggested the ICF-based questionnaire had low criterion validity in terms of being able to identify ASD.

Table 11

Correlations between items on the ICF-based questionnaire and the additional question on ASD

	<u>ASD diagnosis</u> <u>(n = 19)</u>	<u>No ASD diagnosis</u> <u>(n = 50)</u>	
	<u>Mdn (IOR)</u>	<u>Mdn (IOR)</u>	<u>U (z)</u>
'Energy and drive' score	0.00 (2)	0.00 (0)	428.00 (-0.90)
'Control over voluntary movement' score	0.00 (0)	0.00 (0)	528.00 (1.05)
'Involuntary movement' score	0.00 (0)	0.00 (0)	468.50 (-0.25)
Total ICF score	6.00 (11)	8.50 (10)	570.00 (1.28)

* $p < .05$

In Stage 1, the ranges in the responses from the panel brought the content validity of the ICF-based questionnaire into question. The analysis for Hypothesis E also questions the convergent validity of the questionnaire, as a relationship was expected between ICF score and IQ. This hypothesis was therefore partially supported.

3.4 Hypothesis C: The ICF-based questionnaire will discriminate between the three groups of athletes

As shown in Table 12, the DS group had the largest mean ICF score, and the INAS group the lowest. The ICF score significantly differed across the groups. Post-hoc comparisons showed a significant difference between the INAS and DS groups, with a significant number of additional difficulties in the DS group. This difference was not found between the INAS and sub-elite

groups or the sub-elite and DS groups. It should be noted that the effect sizes indicate a medium to large effect for the INAS-DS group comparison, but a small effect for the others. This hypothesis was therefore partially supported.

Table 12

Comparisons between the three groups of athletes on the ICF-based questionnaire

<u>Group</u>	<u><i>n</i></u>	<u><i>M (SD)</i></u>	<u><i>H(2)</i></u>	<u><i>r</i></u>
INAS	26	6.88 (9.29)		
Sub-elite	19	10.26 (7.99)		
DS	32	11.72 (7.49)		
Total	77	9.73 (8.42)	9.81**	
<hr/>				
INAS v sub-elite				-.03
INAS v DS				-.40**
Sub-elite v DS				-.11

* $p < .05$ ** $p < .01$

Figure 1 shows a boxplot for the groups and ICF score. Figures 2 to 4 show the mean scores across the three groups on each item of the questionnaire. This showed the INAS group were more likely to report problems with energy and drive, and with their heart (this may have been explained by an outlier). The sub-elite group were more likely to report problems with: immunity; weight; and breathing, exercise tolerance and heart and breathing functions, which may indicate asthma. The DS group were more likely to report problems with hearing, and on 10 out of the 13 ‘mobility and movement’ items.

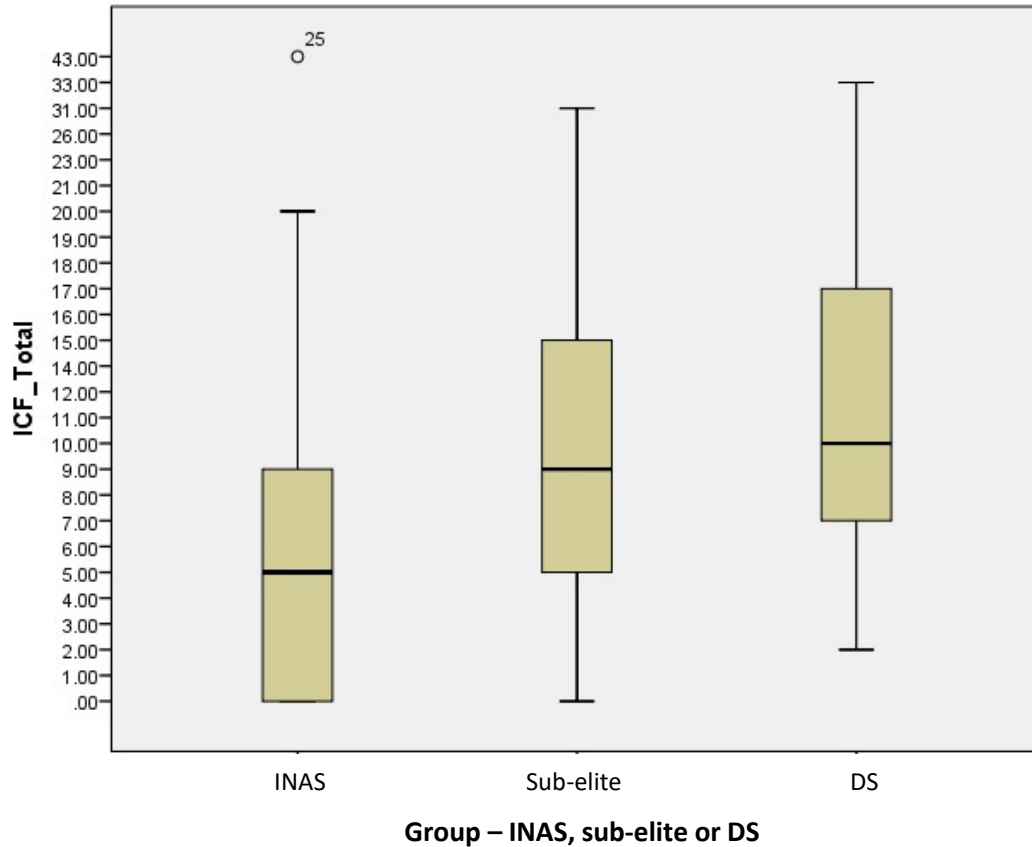


Figure 1: Boxplot of total ICF score by group

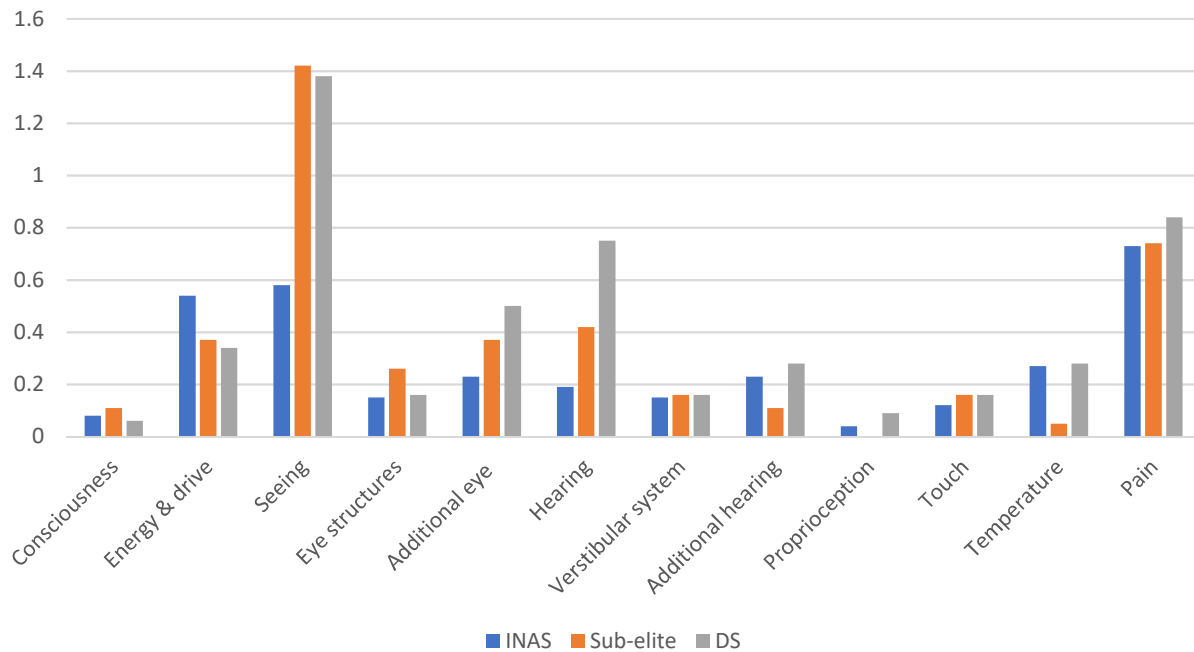


Figure 2: Comparison of the three groups looking at items on the ICF-based questionnaire on senses, pain and consciousness

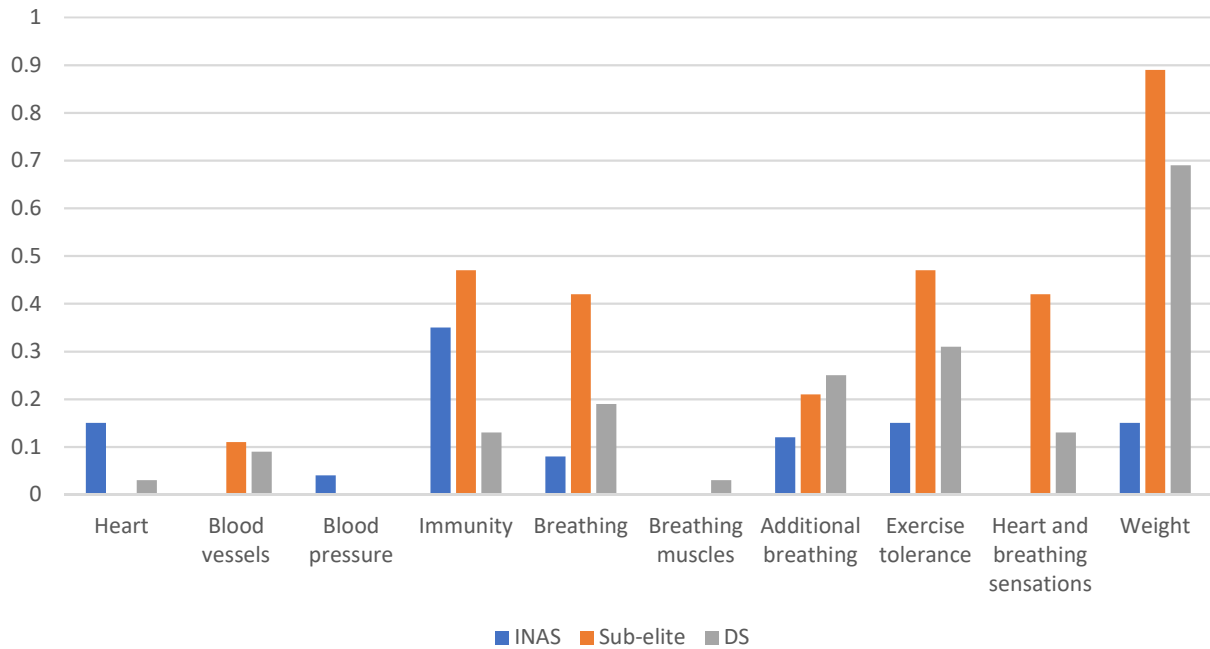


Figure 3: Comparison of the three groups looking at items on the ICF-based questionnaire on the heart, lungs and immune system

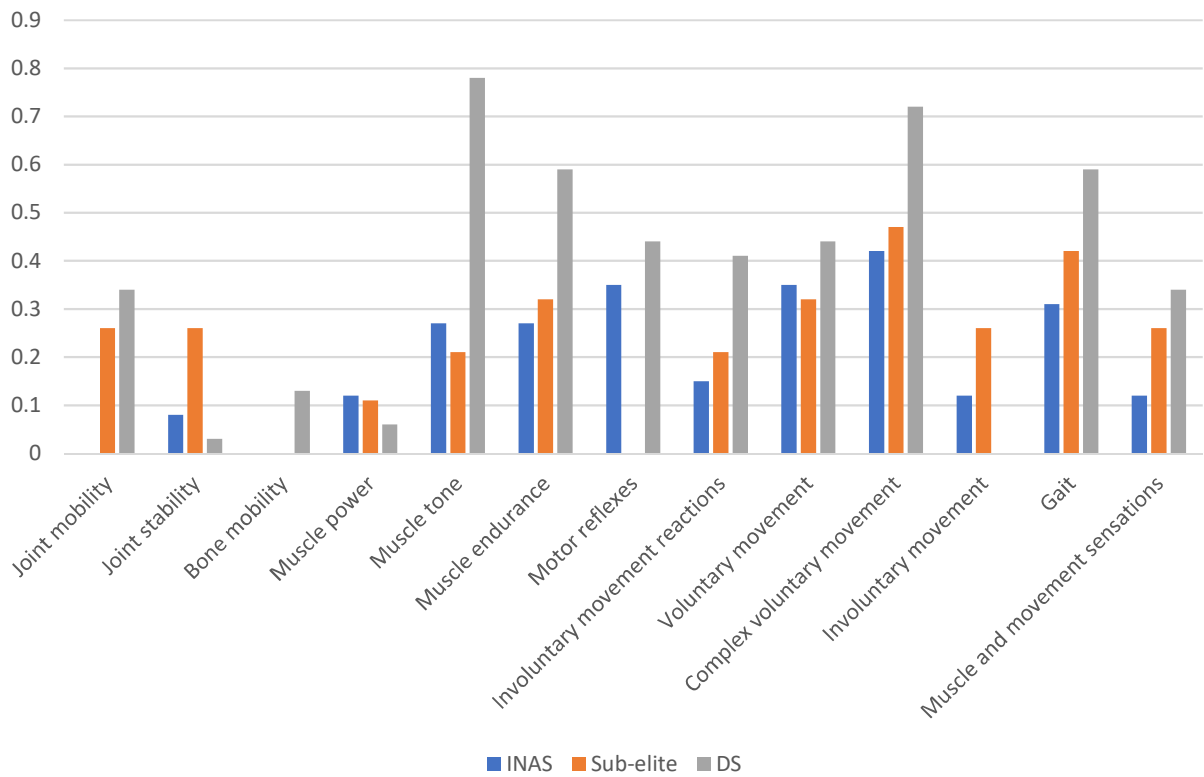


Figure 4: Comparison of the three groups looking at items on the ICF-based questionnaire on movement and mobility

3.5 Hypothesis D: The ICF-based questionnaire will continue to evidence additional difficulties in the sub-elite and DS groups relative to the INAS group, even when IQ is controlled for.

Table 13 contains the mean IQ scores for the groups. There was a significant result for a comparison of IQ between the groups. Post-hoc comparisons revealed significant differences between the INAS and DS groups and the sub-elite and DS groups ($p < .001$), but not between the INAS and sub-elite groups (ns). This supported the importance of controlling for IQ in the analysis.

Table 13
Comparisons between the three groups of athletes on IQ

<u>Group</u>	<u><i>n</i></u>	<u><i>M (SD)</i></u>	<u><i>F(2, 68)</i></u>	<u><i>r</i></u>
INAS	26	62.15 (7.73)		
Sub-elite	17	62.88 (9.14)		
DS	28	52.7 (7.86)		
Total	71	58.59 (9.35)	12.26*	0.51

* $p < .001$

Given that the variables gender, age and years competing (both overall and sport-specific) were not found to have a significant relationship with group these were not included in the regression analysis. The confounding variables that were included, alongside IQ, were those that were shown above to significantly differ between group(s): current health problems; taking medication; and using assistive devices¹. The results are included in Table 14. The overall model was significant. None of the variables predicted whether an athlete was in the INAS or sub-elite

¹ The analysis was also run with age as a variable as it approached significance; this did not markedly affect the results in Table 14.

group. Medication, assistive devices and IQ score all predicted whether an athlete was in the INAS or DS group.

Table 14
Multinomial logistic regression results – all confounding variables

	<i>b (SE)</i>	95% CI for Odds Ratio		
		<u>Lower</u>	<u>Odds Ratio</u>	<u>Upper</u>
Sub-elite vs. INAS				
Intercept	-4.37 (2.98)			
Health	2.84 (1.65)	0.67	17.05	433.76
Medication	-0.99 (1.52)	0.19	0.37	7.32
Assistive devices	1.06 (0.75)	0.67	2.90	12.61
Total ICF score	-0.02 (0.05)	0.89	0.98	1.08
IQ score	0.04 (0.05)	0.95	1.04	1.14
DS vs. INAS				
Intercept	7.81 (3.09)*			
Health	-3.40 (1.84)	0.00	0.03	1.23
Medication	3.60 (1.72)*	1.26	36.48	1053.33
Assistive devices	1.99 (0.82)*	1.48	7.32	36.20
Total ICF score	0.06 (0.05)	0.97	1.07	1.17
IQ score	-0.17 (0.05)**	0.76	0.84	0.94

Notes: $R^2 = .49$ (Cox & Snell), $.56$ (Nagelkerke). Model $X^2 (10) = 48.09$, $p < .001$.

* $p < .05$ ** $p < .01$

A second multinomial logistic regression conducted using just IQ and ICF score as variables did not make a marked difference to the results (Table 15). However, the ICF score between the DS and INAS groups approached significance here ($p = .06$).

These results suggest that, when IQ and other confounding variables were controlled for, the ICF-based questionnaire could no longer be shown to significantly discriminate between the groups. The hypothesis was therefore not supported.

Table 15

Multinomial logistic regression results – IQ and ICF score only

	<i>b</i> (<i>SE</i>)	95% CI for Odds Ratio		
		Lower	Odds Ratio	Upper
Sub-elite vs. INAS				
Intercept	-1.47 (2.48)			
Total ICF score	0.05 (0.04)	0.94	1.01	1.09
IQ score	0.01 (0.04)	0.94	1.01	1.09
DS vs. INAS				
Intercept	7.33 (2.42)**			
Total ICF score	0.08 (0.41)	1.00	1.08	1.17
IQ score	-0.14 (0.04)**	0.80	0.87	0.94

Notes: $R^2 = .30$ (Cox & Snell), $.34$ (Nagelkerke). Model $X^2(4) = 25.24$, $p < .001$.

* $p < .05$ ** $p < .01$

3.6 Hypothesis E: As IQ scores decrease, the overall ICF-based questionnaire score (i.e. the total number of additional disabilities) will increase

Using the whole group, the correlation between ICF score and IQ just failed to reach significance $r = -.17$, $p = .083$. This is illustrated in Figure 5. This was also the case for correlations done by group (INAS $r = -.32$, $p = .058$; Sub-elite $r = .32$, $p = .109$; DS $r = .12$, $p = .279$). This suggested that, contrary to the hypothesis, there was no significant relationship between IQ and ICF score.

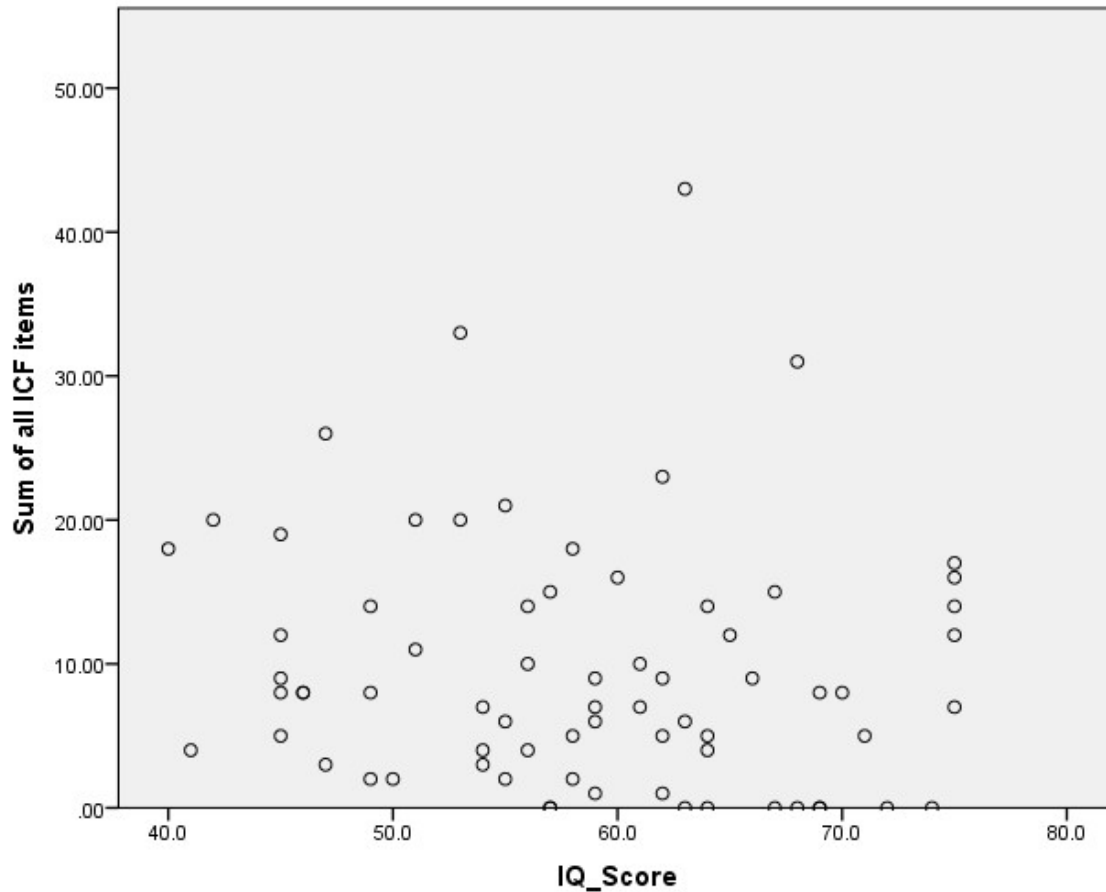


Figure 5: Scatterplot of IQ and total ICF score in the total sample

3.7 Acceptance and practicability

Table 16 shows the responses from the athletes to questions on the post-interview questionnaire. Eighty-seven percent of athletes described the ICF-based questionnaire length as ‘just right’ or ‘long, but OK’, suggesting the administration time was acceptable. Nearly half said they understood all the questions. Additional comments were provided here by 38 athletes, with 16 suggesting they understood when further explanation was given, and 10 because they had someone there to help them.

Table 16

Responses to the post-interview questionnaire

<u>Question</u>	<u>Response</u>	<u>n (%)</u>
What did you think about the length of the interview?	Too short	1 (1.3)
	Just right	47 (61.0)
	Long, but OK	20 (26.0)
	Too long	5 (6.5)
	No response	4 (5.2)
Did you understand the questions?	Yes – all of them	38 (49.4)
	Yes – most of them	25 (32.5)
	Yes – some of them	10 (13.0)
	No	3 (3.9)
	No response	1 (1.3)
Did the questions apply to you?	Yes	56 (72.7)
	No	8 (10.4)
	Some	9 (11.7)
	No response	4 (5.2)
Is there anything I should have asked about that didn't come up today?	Pain in different parts of the body	1 (4.8)
	Constipation	2 (9.5)
	Continence	1 (4.8)
	Kidney function	1 (4.8)
	Dental health	1 (4.8)
	Digestion	3 (14.3)
	Reflux	1 (4.8)
	Feet	2 (9.5)
	Hernia	1 (4.8)
	Diet	2 (9.5)
	Body proportions	2 (9.5)
	Sensitivity to noise	1 (4.8)
	Flat back of head	1 (4.8)
	Thyroid	2 (9.5)

4. Discussion

The main aim of this study was to develop and pilot a tool that could provide a platform for the development of a taxonomy of ID that included physical health alongside IQ. This was with a view to providing a basis for future research that could examine the validity and utility of such a taxonomy for PWID more generally. To address this, a panel of experts were consulted to

develop an ICF-based questionnaire for PWID. There was a range of opinions across the expert panel regarding which physical health problems would be important to include in the ICF-based questionnaire. There were also further suggestions from participants, such as digestion.

Nevertheless, the ICF-based questionnaire had satisfactory internal consistency, supporting the combination of these items into one score.

However, this process also demonstrated the difficulty of building a questionnaire for the ‘typical’ person with ID. This study helped to further illustrate that there is no such person, and a broad range of physical health problems are common to PWID (Cooper et al., 2015; Howells; 1997). This may help to explain some of the limitations of the questionnaire (see section 4.1).

This questionnaire was then piloted with 77 athletes with ID, with the aim of establishing whether it: was reliable and valid; could discriminate between the three groups of athletes, even when IQ was controlled for; and whether a decrease in IQ would be accompanied by a decrease in ICF score.

There was a significant difference between the INAS and DS groups for use of assistive devices and whether these could be worn whilst playing sport. This suggested use of assistive devices should be considered when establishing competing categories for athletes with DS. A significant difference was found for reported current physical health between the INAS and sub-elite groups. Whilst there was an overall significant result for whether the athletes were taking medication, post-hoc comparisons only approached significance between the INAS and sub-elite groups. This is an important factor to consider when evaluating the ICF-based questionnaire, as athletes may have reported no physical health problem (for example with blood pressure) if this was well controlled with medication (athletes, and the person accompanying them, found it difficult to say how much of a problem something would be if they were not taking medication).

These findings showing differences between the groups in physical health were supported by results from the ICF-based questionnaire, which found an overall significant difference between the groups. However, a significant difference was only found between the INAS and DS groups. This indicated that, as hypothesised, the INAS group had the least physical health problems between the groups, and the DS group the most. The lack of a difference between the INAS and sub-elite groups here may have been the result of Type II errors (see section 4.1).

In terms of IQ, a significant difference was found between the DS group and the others, but not between the INAS and sub-elite groups. Both regression analyses comparing the sub-elite and INAS groups gave no significant results. This did not support the hypothesis that there would be a difference in the ICF score between these groups when IQ was controlled for.

This hypothesis was also not supported when comparing the INAS and DS groups. However, when using just IQ and ICF-score as variables this approached significance. The IQ score between these groups remained a significant predictor in the first regression analysis, as did medication and assistive devices. This suggested that, with a larger sample, the ICF score may be able to distinguish between the INAS and DS groups, even when IQ is controlled for. At this stage, even if the ICF-based questionnaire is discounted, there are significant differences between the INAS and DS groups that warrant consideration of a further competing category. It may be that, whilst sports performance has not been related to IQ, IQ plays a mediating role, for example in effective training (Burns, 2015). This would be an area for further research.

It is interesting that these differences were found between the DS and INAS groups but not the sub-elite and INAS groups. This might suggest there is no need to widen the current competing categories for athletes with ID for this group. However, a significant difference was found between these groups on self-reported current health problems, and this approached

significance for medication. This suggested there may be a difference the ICF-based questionnaire was not sensitive enough to capture. This could also link to the limitations above regarding measuring health problems when taking medication.

It might be suggested from this that the ICF-based questionnaire was better at identifying physical health problems in the DS group than in the sub-elite group. This is perhaps unsurprising, as DS is likely to result in more severe, long-standing physical health problems compared to the more diverse sub-elite group (Abbag, 2006). This, combined with a lack of power, may have made it easier for the analyses to identify a significant difference between the INAS and DS groups, but not the INAS and sub-elite groups.

This study found no significant support for the hypothesis that a decrease in IQ would be accompanied by a decrease in physical health, as measured by the ICF-based questionnaire. This could not be explained by the lack of range in IQ scores, which covered 'severe' ID (FSIQ of 55 and below; BPS, 2015). Past research has shown this result in quite specific areas of physical health, so it may be this result does not hold up to a wider view of physical health. However, intuitively, this does not seem like a plausible explanation, particularly considering research on PIMD (Nakken & Vlaskamp, 2007). It should be highlighted that the results were approaching significance, suggesting there would be value in collecting a larger sample to test if this result was due to low power.

4.1 Limitations

The sample size of this study produced a major limitation. Although the recruitment target was met for the DS group, this was not the case for the INAS and, particularly, the sub-elite groups. Unfortunately, it proved difficult to recruit at events: athletes were often tied to busy schedules,

or could not be accompanied by someone who knew them well. Interviews, with non-INAS athletes, also took around an hour to complete, which was difficult to accomplish in the time available at events and clubs.

Non-significant findings may therefore be Type II errors due to lack of power of the statistical tests to detect smaller effects. This was particularly the case for the smaller sub-elite group, and in the regression analysis, for which the original power analysis was conducted (section 2.6.5). This suggested that conclusions drawn from this study, particularly regarding the utility of the ICF-based questionnaire, should be made with caution.

Although the reliability analysis for the full ICF-score produced a result within the acceptable range, this may partially be due to the number of items in the scale artificially increasing the alpha (Field, 2013). One way to examine this would be to conduct a Principal Component Analysis (PCA) to explore for factors in the questionnaire. This would also help to further evaluate its validity. This was not conducted as more participants would be needed to make this a meaningful analysis (Field, 2013).

The measured validity of the ICF-based questionnaire was limited. This suggested the questionnaire could benefit from further development. Having a larger sample size may improve the results of the validity analysis so far, and allow for comparisons regarding epilepsy and cerebral palsy. The number of items that could be cross-referenced from the ASD core set was also a limitation (three out of 16 items). It was difficult to include more items whilst keeping the ICF-based questionnaire an acceptable length. Given the responses from athletes on the length of the questionnaire, the number of items could be increased to produce a longer, but more thorough, assessment of physical health. Additional items could include reported difficulties with constipation and thyroid problems.

Information on IQ was missing for 6 athletes (7.8%). It could be argued these athletes should not have been included as they may not have met the inclusion criteria. However, the likelihood of this, compared to the percentage of athletes that agreed to take part who had an IQ measured as over 75 (7.7%), was deemed to be acceptably low.

4.2 Practical implications

Although the utility of the ICF-based questionnaire requires further scrutiny, this study illustrates that such a tool can be developed and used directly with PWID. The acceptability and practicality of the ICF-based questionnaire were judged by participants as high. However, the results also suggested that such questionnaires should be administered by a person trained to give further explanations, and with someone present who knows the PWID well.

These results support further work towards implementation of a distinct competing class for athletes with DS. Whilst it could be suggested this be done based on diagnosis alone, foregoing a taxonomic approach has been cautioned against (Tweedy, 2002). DS is also a varied population, consisting of different types with different difficulties (National Down Syndrome Society, 2018). Here the ICF-based questionnaire has potential, to help ensure all athletes with DS have similar bodily functions. There could be potential for sub-elite athletes to compete in this hypothesised category, again by using the ICF-based questionnaire to check for equivalence, although further research may be needed to support this. The findings also suggest it would be useful to check for equivalence in terms of IQ, use of assistive devices and use of medication.

This study has helped to illustrate the wide range of physical health problems that PWID present with (Figures 2-4). This is even more notable given the sample consisted of athletes, who would likely be healthier compared to the rest of the ID population. This suggests a taxonomic

approach to ID may be a valid and useful approach. This also suggests that a tool such as the ICF-based questionnaire may have potential usefulness as a guide and aid to clinicians to help them to assess PWID and to help ensure problems with physical health are not overlooked. This in turn has the potential to help reduce issues such as diagnostic overshadowing in PWID.

This also has implications for clinical psychologists. Currently, services for PWID are provided on the basis of meeting that diagnosis. Clinical psychologists are often the profession that provide this diagnosis, and they can therefore be seen as the 'gatekeepers' to services. Webb and Whitaker (2012) have argued, from the perspective of IQ, that services for PWLD should instead be provided on a needs-led basis as, for example, someone with an IQ of 80 may require more help and support than someone with an IQ of 60. This research helps to support this approach, and broadens it further to help illustrate a holistic approach to need that includes physical health.

4.3 Further research

Further research could expand this work by building a larger dataset to help correct the power issues encountered during this study. This would make it more feasible to explore for factors in the questionnaire using a PCA analysis. It would allow the data to be analysed further based on specific physical health problems, like asthma, epilepsy and cerebral palsy. Useful additions to the methodology to assess validity would be the inclusion of an additional questionnaire on physical health, or comparison with medical records. Consideration should also be made for the impact of medication on completion of the ICF-based questionnaire, perhaps through the inclusion of additional items on this.

Further research is needed to elucidate the barriers for the sub-elite group in accessing elite sport. A larger sample may help establish any effects of IQ and physical health. There may be additional practical issues here worth exploring, such as knowledge of organisations such as INAS, and the financial and practical support to access such organisations and their events.

Finally, additional research could build on this work to further consider how we think of and define ID. One way to do this would be to work towards building an ICF Core Set for ID. This would not only include physical health but the environmental and activities and participation factors within the ICF. This would expand the taxonomy of ID to include the full biopsychosocial model.

5. Conclusion

Given the limitations of this study, conclusions need to be made with caution. However, the results so far suggest that a separate competing category for athletes with Down Syndrome should be considered, as this group could currently be considered disadvantaged in terms of their physical abilities when compared to athletes that currently compete with INAS. More research needs to be done to consider what a competing category(ies) for other (sub-elite) athletes would consist of, but this study indicates that further investigation would be warranted.

This study has produced an ICF-based questionnaire for identifying physical health problems in PWID. Whilst this questionnaire requires further adaptation, it supplies a building block for further research in this area. It is hoped this will inspire further debate on a taxonomy for intellectual disabilities and the potential advantages of this, particularly in helping to ensure physical health problems in this population are not overlooked.

6. References

- Abbag F. I. (2006). Congenital heart diseases and other major anomalies in patients with Down syndrome. *Saudi Medical Journal*, 27, 219–222. Retrieved from:
<https://www.smj.org.sa/index.php/smj/article/view/3530>
- Aljunied, M., & Frederickson, N. (2014). Utility of the International Classification of Functioning, Disability and Health (ICF) for educational psychologists' work. *Educational Psychology in Practice*, 30, 380–392.
<http://dx.doi.org/10.1080/02667363.2014.949627>
- Arevalo, M. (2001). Influences on health. In J. Thompson & S. Pickering (Eds.), *Meeting the health needs of people who have a learning disability* (pp. 41-62). London: Harcourt Publishers Limited.
- Barnes, C., & Mercer, G. (2010). *Exploring disability* (2nd ed.). Cambridge: Polity.
- Battaglia, M., Russo, E., Bolla, A., Chiusso, A., Bertelli, S., Pellegrini, A., ... & Martinuzzi, A. (2004). International Classification of Functioning, Disability and Health in a cohort of children with cognitive, motor, and complex disabilities. *Developmental Medicine and Child Neurology*, 46, 98-106. <https://doi.org/10.1017/S0012162204000209>
- Baynard T., Pitetti K. H., Guerra M. & Fernhall B. (2004). Heart rate variability at rest and during exercise in persons with Down syndrome. *Archives of Physical Medicine and Rehabilitation*, 85, 1285–1290. doi:10.1016/j.apmr.2003.11.023
- Baynard T., Pitetti K. H., Guerra M., Unnithan V. B. & Fernhall B. (2008). Age-related changes in aerobic capacity in individuals with mental retardation: a 20-yr review. *Medicine and Science in Sports and Exercise*, 40, 1984–1989. doi:10.1249/MSS.0b013e31817f19a1

Bölte, S., Mahdi, S., & Selb M (2016) ICF(-CY) core sets for ASD. Stockholm, Nottwil: Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND), Swiss Paraplegic Research, ICF Research Branch.

British Psychological Society (2008). *Discussion paper: Socially inclusive practice*. Retrieved from:

http://www.bps.org.uk/sites/default/files/documents/socially_inclusive_practice_discussion_paper.pdf

British Psychological Society (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. Available from: <https://shop.bps.org.uk/guidance-on-the-assessment-and-diagnosis-of-intellectual-disabilities-in-adulthood.html>

Buntix, W. H. E., & Schalock, R. L. (2010). Model of disability, quality of life, and individualized supports: implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 283-294.

Burns, J. (2015). The impact of intellectual disabilities on elite sports performance. *International Review of Sport and Exercise Psychology*, 8, 251-267.
doi:10.1080/1750984X.2015.1068830

Cameron, L., & Murphy, J. (2006). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35, 113–120. doi:10.1111/j.1468-3156.2006.00404.x

Cerniauskaite, M., Ajovalasit, D., Quintas, R., Alvarez, A., Franceschetti, S., Casazza, M., ... Leonardi, M. (2012). Functioning and disability in persons with epilepsy. *American*

Journal of Physical Medicine & Rehabilitation, 91 (Suppl. 1), 22-30.

doi:10.1097/PHM.0b013e31823d4d6f.

Clark-Carter, D. (2010). *Quantitative psychological research: The complete student's companion* (3rd ed.). Hove: Psychology Press.

Cooper, S-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice, 16*(110). doi:10.1186/s12875-015-0329-3

Cooper, S-A., Hughes-McCormack, L., Greenlaw, N., McConnachie, A., Allan, L., Baltzer, M., ... Morrison, J. (2018). Management and prevalence of long- term conditions in primary health care for adults with intellectual disabilities compared with the general population: a population- based cohort study. *Journal of Applied Research in Intellectual Disabilities, 31*, (Suppl. 1), 68–81. doi:10.1111/jar.12386

Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *International Journal for Equity in Health, 15*, 1-9. doi:10.1186/s12939-016-0296-x

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. (4th ed.). London: Sage.

Finkelstein, V. (2001). *A personal journey into disability politics*. Retrieved from:
<https://www.independentliving.org/docs3/finkelstein01a.pdf>

Fleishman, E. A., & Quaintance, M. K. (1984). *Taxonomies of human performance: The description of human tasks*. Orlando: Harcourt Brace Jovanovich.

Gilderthorp, R. (2015). *Sports participation for people with learning disabilities: An investigation of the factors that predict the performance of athletes with intellectual*

- disability* (Unpublished doctoral dissertation). Salomons, Canterbury Christ Church University.
- Grant, P. (2017, September 17). Paralympic Sport – Fair Play? *File on 4*. Podcast retrieved from <http://www.bbc.co.uk/programmes/b0952qqf>
- Howells, G. (1997). A general practice perspective. In J O'Hara & A. Sperlinger (Eds.), *Adults with Learning Disabilities: A Practical Approach for Health Professionals* (pp. 61–79). Chichester: John Wiley and Sons.
- Huitt, W. (2011). *Bloom et al.'s taxonomy of the cognitive domain*. Retrieved from <http://www.edpsycinteractive.org/topics/cognition/bloom.html> [[pdf](#)]
- Hutzler, Y., & Korsensky, O. (2010). Motivational correlates of physical activity in persons with an intellectual disability: a systematic literature review. *Journal of Intellectual Disability Research*, 54, 767-786. doi:10.1111/j.1365-2788.2010.01313.x
- INAS (2016). *Section 4: Policies. 4.1: INAS eligibility & classification: rules and procedure*. Retrieved from: <http://www.inas.org/wp-content/uploads/2010/11/4.1-Eligibility-Classification-Policy5.pdf>
- International Paralympic Committee (n.d.). *Layman's guide to Paralympic classification*. Retrieved from https://www.paralympic.org/sites/default/files/document/120716152047682_ClassificationGuide_2.pdf
- Jelsma, J. (2009). Use of the International Classification of Functioning, Disability and Health: a literature survey. *Journal of Rehabilitation Medicine*, 41, 1-12. doi:10.2340/16501977-0300

- John O. P. (1989). Towards a Taxonomy of Personality Descriptors. In D. M. Buss & N. Cantor (Eds.), *Personality Psychology*. Available from:
https://link.springer.com/chapter/10.1007/978-1-4684-0634-4_20#citeas
- Kohler, F., Xu, J., Silva-Withmory, C., & Arockiam, J. (2001). Feasibility of using a checklist based on the international classification of functioning, disability and health as an outcome measure in individuals following lower limb amputation. *Prosthetics and Orthotics International*, 35, 294–301. doi:10.1177/0309364611415310
- Kostanjsek, N. (2011). Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health*, 11(4), 1-6. doi:10.1186/1471-2458-11-S4-S3
- Lahtinen, U., Rintala, P., & Malin, A. (2007). Physical performance of individuals with intellectual disability: A 30-year follow-up. *Adapted Physical Health Quarterly*, 24(2), 125-143. Available from
<http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=3&sid=387a3b82-820c-4f2b-ac63-a296f8aa1c07%40sessionmgr107&hid=110>
- Maeda, S., Kita, F., Miyawaki, T., Takeuchi, K., Ishia, R., Egusa, M., & Shimada, M. (2005). Assessment of patients with intellectual disability using the International Classification of Functioning, Disability and Health to evaluate dental treatment tolerability. *Journal of Intellectual Disability Research*, 49, 253-259. <https://doi.org/10.1111/j.1365-2788.2005.00644.x>
- Mencap (2007). *Death by indifference*. Retrieved from:
http://www.pmlndnetwork.org/resources/death_indifference_report_easyread.pdf

Mencap (2012). *Death by indifference: 74 deaths and counting. A progress report 5 years on.*

Retrieved from: <http://vodg.org.uk/uploads/pdfs/Death%20by%20Indifference.pdf>

Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*, 83-87.

doi:10.1111/j.1741-1130.2007.00104.x

National Down Syndrome Society. (2018). *Down Syndrome*. Retrieved from:

<https://www.ndss.org/about-down-syndrome/down-syndrome/>

Orellove, F. P., Wehman, P., & Wood, J. (1982). An Evaluative Review of Special Olympics:

Implications for Community Integration. *Education and Training of the Mentally*

Retarded, 17, 325-329. Retrieved from: <http://www.jstor.org/stable/23877302>

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I., (2002). Life expectancy of

people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual*

Disability Research, 44, 591-599. doi:10.1046/j.1365-2788.2000.00280.x

Robertson, J., Roberts, H., & Emerson, E. (2010). *Health checks for people with learning*

disabilities: A systematic review of evidence. Retrieved from:

http://webarchive.nationalarchives.gov.uk/20160704171248/https://www.improvinghealthlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence

http://webarchive.nationalarchives.gov.uk/20160704171248/https://www.improvinghealthlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence

http://webarchive.nationalarchives.gov.uk/20160704171248/https://www.improvinghealthlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence

Salvador-Carulla, L., Reed, G. M., Vaez-Azizi, L. M., Cooper, S-A., Martinez-Leal, R., Bertelli,

M., ... Saxena, S. (2011). Intellectual developmental disorders: towards a new name,

definition and framework for “mental retardation/intellectual disability” in ICD-11.

World Psychiatry, 10, 175-180. doi:10.1002/j.2051-5545.2011.tb00045.x

- Schiariti, V., Selb, M., Cieza, A., & O'Donnell, M. (2015). International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy: a consensus meeting. *Developmental Medicine & Child Neurology*, *57*, 149-158.
doi:10.1111/dmcn.12551
- Selb, M., Escorpizo, R., Kostanjsek, N., Stucki, G., Üstün, B., & Cieza, A. (2015). A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. *European Journal of Physical and Rehabilitation Medicine*, *51*, 105-117. Retrieved from: <http://www.minervamedica.it/en/journals/europa-medicophysica/article.php?cod=R33Y2015N01A0105>
- Shakespeare, T. (2006). *Disability rights and wrongs*. Retrieved from: <https://books.google.co.uk/books?id=aBKAAgAAQBAJ>
- Sperlinger, A. (1997). Introduction. In J O'Hara & A. Sperlinger (Eds.), *Adults with Learning Disabilities: A Practical Approach for Health Professionals* (pp. 61–79). Chichester: John Wiley and Sons.
- Stucki, A., Daansen, P., Fuessl, M., Cieza, A., Huber, E., Atkinson, R., ... Ruof, J. (2004). ICF Core Sets for obesity. *Journal of Rehabilitation Medicine*, *44* (Suppl.), 107-113.
doi:10.1080/16501960410016064
- Sweeney, M. R., Staines, A., Corby, D., McVeigh, T., McKeon, M., Lambert, V., ... Griffin, P. (2016). *The SOPHIE (Special Olympics programmes health impact evaluation) study report, 2013-2015*. Retrieved from: <http://www.specialolympics.ie/WHOWEARE.aspx>
- Thomas, D., & Woods, H. (2003). *Working with people with learning disabilities: Theory and Practice*. Retrieved from: <https://books.google.co.uk/books?id=y6VqcpaZiEQC&printsec=frontcover&dq=W>

orking+with+People+with+Learning+Disabilities:+Theory+and+Practice&hl=en&sa=X
&ved=0ahUKEwiH8J2OiZTOAhUnl8AKHT97BmwQ6AEIHjAA#v=onepage&q=Work
ing%20with%20People%20with%20Learning%20Disabilities%3A%20Theory%20and%
20Practice&f=false

- Turner, S. (2001). Health needs of people who have a learning disability. In J. Thompson & S. Pickering (Eds.), *Meeting the health needs of people who have a learning disability* (pp. 63-88). London: Harcourt Publishers Limited.
- Tweedy, S. M. (2002). Taxonomic theory and the ICF: Foundations for a unified disability athletics classification. *Adapted Physical Activity Quarterly*, *19*, 220-237.
- Tweedy, S. M., & Vanlandewijck, Y. C. (2009). International Paralympic Committee position stand - background and scientific principles of classification in Paralympic sport. *British Journal of Sports Medicine*, published online 22 October 2009, doi:10.1136/bjism.2009.065060
- van Timmeren, E. A., van der Putten, A. A. J., van Schrojenstein Lantman-de Valk, H. M. J., van der Schans, C. P. & Waninge, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research*, *60*, 1109-1118. doi:10.1111/jir.12298
- van Schrojenstein Lantman-De Valk, H. M. J., Metsemakers, J. F. M., Haveman, M. J., & Crebolder, H. F. J. M. (2000). Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice*, *17*, 405-407. doi:10.1093/fampra/17.5.405

- Walsh, D. (2017, August 20). In a culture of bullying, intimidation and harassment, Britain is No 1 in the league of cheating nations when it comes to classifying disabled athletes. *The Sunday Times*, p. 16.
- Webb, J., & Whitaker, S. (2012). Defining learning disability. *The Psychologist*, 25, 440-443.
- Wechsler, D. (2011). *Wechsler Abbreviated Scale of Intelligence (WASI-II): Manual* (2nd ed.). Bloomington, MN: Pearson.
- Wen, X. (1997). *The definition and prevalence of intellectual disability in Australia*. Retrieved from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442455468>
- World Health Organisation (1992). *ICD-10: The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation.
- World Health Organisation (2001). *ICF: International classification of functioning, disability and health*. Geneva: World Health Organisation.
- World Health Organisation. (2003). *ICF Checklist Version 2.1a, Clinical Form for International Classification of Functioning, Disability and Health*. Retrieved from: <http://www.who.int/classifications/icf/icfchecklist.pdf>

Appendix A: Critiques of Part A studies against criteria

Table i:

Studies critiqued against Yin's (2014) case study criteria

<u>Authors</u>	<u>Significant?</u>	<u>Complete?</u>	<u>Alternative perspectives considered?</u>	<u>Sufficient evidence?</u>	<u>Engaging?</u>	<u>Include?</u>
Tuffrey-Wijne (2002)	Yes – lack of other research, relates to government policy. Includes practical recommendations, although these could have been made clearer.	Yes. Includes definition of ID. Very clear multi-methodology described.	This was an exploratory study which found five themes.	Yes – very clear multi-methodology described. Illustrative quotes from interviews used.	Yes – discursive style with good use of examples	Yes
Brown, Burns & Flynn (2003)*	Partly – lack of other research, but context not made clear.	Partly – clear description of findings, but the number of case studies made it difficult to ascertain how examples were chosen.	Partly – some consideration of exceptions to findings, but the again the number of case studies made it difficult to ascertain how examples were chosen.	Yes – variety of methods used, including mapping the trajectory of the illness and how it had been managed over time; interviews with staff, carers and people with LD; use of support network maps	Yes – discursive style with good use of examples	Yes
Bishop, Robinson & VanLare (2013)	Yes – lack of other research, use of theory and provides recommendations	No - Includes definition of LD, but only a short illustrative example so detail is missing	No - Little exploration of the potential reasons for the misdiagnosis	No - only a short illustrative example so detail is missing	Yes – discursive style with good use of examples	No

*included here using Yin's (2004) definition of multiple case studies

Table ii:

Studies critiqued against Critical Appraisal Skills Programme Qualitative Research Checklist (2017)

	<u>Ali et al. (2013)</u>	<u>Dinsmore (2011)</u>	<u>Minnes & Steiner (2009)</u>	<u>Sowney & Barr (2006)</u>	<u>While & Clark (2014)</u>
1. Was there a clear statement of the aims of the research?	Yes – clear aims and objectives section	Yes – clear aims	Yes - Objectives set out and linked to research.	Yes – clear research-based aim	Yes – clear aim
2. Is a qualitative methodology appropriate?	Yes - research seeks to highlight the subjective experiences of research participants	Yes - research seeks to highlight the subjective experiences of research participants	Yes - research seeks to highlight the subjective experiences of research participants and choice of participants clearly linked to research	Yes	Yes, to address this research goal
3. Was the research design appropriate to address the aims of the research?	Yes, but not clearly discussed	Yes, but not clearly discussed	Yes	Yes, but not clearly discussed	Yes, but not clearly discussed
4. Was the recruitment strategy appropriate to the aims of the research?	Partly – explained how participants were selected but incomplete discussion of why those participants were most appropriate, and no discussion of why people why not choose to take part	Yes, although no discussion of why people why not choose to take part	Yes, although no discussion of why people why not choose to take part	Yes, although no discussion of why people why not choose to take part	Recruitment strategy unclear

5. Was the data collected in a way that addressed the research issue?	Yes – methods clear and justified.	Yes – clear interview structure and sources for research questions. Form of data is clear, but did not discuss saturation of data.	Partly – clear how data collected and form of data, but needed more information on interview questions.	Partly - Clear form of data and data collection, but not why this method was chosen.	Partly – clear how data collected using research-based topic guides. However, saturation of the data and form of data not discussed.
6. Has the relationship between researcher and participants been adequately considered?	Partly – the authors talk about their intent to talk about this in a separate Box. Whilst this does not appear in either the online or PDF versions, some consideration is made in a later Table.	Partly – some consideration of how their role may have produced a bias.	Not discussed	Not discussed	Not discussed
7. Have ethical issues been taken into consideration?	Yes – ethics statement included, with detailed discussion of consent	Partly – through discussion of consent	Partly – some discussion of confidentiality	Yes – clear ethics section	Mostly – ‘ethical considerations’ and ‘ethical approval’ sections, but did not cover working with people with LD
8. Was the data analysis sufficiently rigorous?	Yes. Additional rater used and inter-rater reliability discussed.	Partly - Analysis process referenced but not written about in detail. Good use of supportive quotes. Some acknowledge-	Partly – discussion of consensus seeking amongst researchers and participants. Good use of supportive	Partly – only refers to a ‘qualitative design’ with no specific methodology, and no consideration of own role and	Partly – some description of procedure and themes analysed by two researchers, but insufficient

		ment of mixed and contradictory findings. Limited discussion of own role and potential bias.	quotes. No discussion of own role and potential bias.	potential biases. But good use of data (including non-verbal) to support findings and consideration of contradictory data.	data presented.
9. Is there a clear statement of findings?	Yes –considers participants bias and that the findings may be same of other patients e.g. elderly	Yes. Explicit findings related to the research aims, and clearly states research limitations.	Yes. Explicit findings related to the research aims, and clearly states research limitations.	Credibility of findings considered.	Yes, including discussion of limitations and alternative explanations.
10. How valuable is the research?	Yes – recommendations clearly made, along with implications and areas for further research	Yes – recommendations made and clearly linked to themes.	Partly – some recommendations made but limited by scale of research.	Yes – recommendations clearly made, along with implications and areas for further research	Yes – results discussed in relation to current policy and further research. Implications for nursing management discussed.

Appendix B: University Ethics Panel approval

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Appendix C: Information sheets



Information about the research

Physical health in athletes with intellectual disabilities



Hi! My name's **Suzie Lemmey**. I'm a trainee clinical psychologist.



I'm **studying** at the Salomons Centre, part of Canterbury Christ Church University.



Are you **18 years old, or older?**

I would like to **invite you** to take part in a research study.



Before you decide it is important that you **understand** why the research is being done and what I will ask you to do.

Please talk with someone you trust about this **information sheet**.

Why are we doing this study?



I'm doing **research** with **INAS**, the International Sports Federation for Persons with Intellectual Disability, and **Canterbury Christ Church University**. They are paying for the research.



We want to get more people with intellectual disabilities to take part in **sport**.

We think that **physical health** is important. We think it might be stopping some people with intellectual disabilities taking part in sports.

Why have I been invited?



I am going to be talking with people with intellectual disabilities that compete at all sorts of different **sporting events**.

I am going to aim to talk to **100 people!**

Do I have to take part?



You **do not have** to talk to me!



If you agree to take part, I will ask you to sign a **consent form**. That means that you agree to take part in the study.



You can **change your mind** at any time. No one will think badly of you if you do this. If you change your mind we would not use what you say in the study.

What will happen to me if I take part?



You can talk to me with someone that **you trust**, like your coach, a family member or friend.



I would **ask you questions** about your physical health.



We would talk for about **30 minutes**.

I would **write down** your answers on a computer.

What could be bad about taking part?



It could be quite **tiring** answering lots of questions. But you can ask for a break if you are feeling tired.



I will be asking you questions about your physical health. This could feel **difficult** or **embarrassing**. You do not need to answer all the questions. But you can talk about it if you want to.



Other people have taken part in a project like this before. They found it **OK**.

What could be good about taking part?



We cannot promise that the study will help **you**.

But we hope that this study will help people with intellectual disabilities and physical health disabilities to **take part** in all sport events.

Will anyone know I have taken part?

~~NAME~~

I would keep what you say **anonymous**. This means that we would not use your name, and no one would know that you took part.



But it's not a secret! You can tell people that you have taken part, if you want to!



I would keep what you say **safe**. It will be kept on a laptop. A password is needed to open the laptop.

Only myself and my supervisor will look at what you say.

We will keep what you say for **five years**. After that we will delete all of the information.

What will happen to what I say?



We will **let you know** what we found out. We will do this by putting information on the INAS website.



We hope to let other people know what we find. We will do this by writing a paper which could be **printed** or be put on the **internet**.



This paper would talk about **everyone together**. No one reading the paper will be able to tell that you took part, unless you tell them.

What if there is a problem?



If you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions.

Email: s.lemmey487@canterbury.ac.uk



You can leave a message for me on a 24-hour voicemail phone line:

(00 44) 1227 927070.



Please say that the message is for me (Suzie Lemmey) and leave a contact number so that I can get back to you.

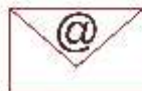


If you are still unhappy and wish to complain you can contact:

Professor Paul Camic, Research Director



Salomons Centre for Applied Psychology,
1 Meadow Road, Tunbridge Wells, Kent
TN1 2YG.



Email: Paul.camic@canterbury.ac.uk

Tel: (00 44) 1227 927114



If you agree to take part, I will ask you to sign a **consent form**. That means that you agree to take part in the study.



You can **change your mind** at any time. No one will think badly of you if you do this. If you change your mind we would not use what you say in the study.

What will happen to me if I take part?



You could talk to me with someone that **you trust**, like your coach, a family member or friend.



I would **come and meet you**. We would talk about where would be best to meet.

I would **ask you questions** about your physical health.

Added to information sheets for non-INAS athletes



I would also do a **short assessment** with you. This would be to look at what you are great at and what you are not so good at. This is **optional** – you do not have to do this part.



We would talk for up to **one hour**.

We do not have to complete everything in one go! We could meet several times, even over Skype!

I would **write down** your answers on a computer.

Amended in information sheets for non-INAS athletes

What could be bad about taking part?



It could be quite **tiring** answering lots of questions. But you can ask for a break if you are feeling tired.



I will be asking you questions about your physical health. This could feel **difficult** or **embarrassing**. You do not need to answer all the questions. But you can talk about it if you want to.



Other people have taken part in a project like this before. They found it **OK**.

What could be good about taking part?



We cannot promise that the study will help **you**.

But we hope that this study will help people with intellectual disabilities and physical health disabilities to **take part** in all sport events.



Physical health in athletes with intellectual disabilities:
Information about the research for people attending with
participants

Hello. My name is Suzie Lemmey and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study alongside the person you know who is an athlete with an intellectual disability (ID). Before you decide it is important that you understand why the research is being done and what it would involve for you.

Please feel free to talk to others about the study if you wish. Please also read the information sheet for athletes for further details.

What is the purpose of the study?

The purpose of the study is to explore physical and sensory abilities in athletes with ID. We are also exploring the relationship between these and intelligence (i.e. IQ). The reason for this is that, currently, there is only one competing class for athletes with ID at elite levels. This means that athletes with additional physical and/or sensory disabilities are often unable to compete at this level. We are working towards developing an additional competing class for athletes with ID, and hope that the information that we obtain in this research will be a step towards this goal. We also think that the findings may have implications for how ID is viewed more globally, i.e. as more than just IQ.

Why have I been invited?

We will be interviewing athletes with intellectual disabilities about any physical and sensory difficulties that they experience. We may also be asking them to take part in a short assessment to establish their IQ, if we do not already have this information. We are asking for someone who has a good relationship with the athlete and knows them and their medical history well to join the interview and help answer questions. It is therefore also important that you speak English. You could be the athlete's coach, a family member or a friend.

Do I have to take part?

It is up to you to decide to join the study. If the athlete you know agrees to take part I will ask them to sign a consent form.

What will happen to me if I take part?

If you and the athlete agree to take part I will come and meet you both at a place convenient to you. I will talk over the research with both of you and ensure that you both want to continue with the interview. The interview itself will be based on the International Classification of Functioning, Disability and Health developed by the World Health Organisation. I may also be asking the athlete to complete a short assessment of their IQ.

The full interview will last between 30 minutes and an hour. I will use a laptop to record the answers to the interview. At the end I will also ask for some feedback on how you both found the interview.

What will I have to do?

I will be addressing questions to the athlete. However, as some of the questions will be quite specific, it will be valuable to have you there to help answer and, if necessary, translate questions. We will talk at the beginning of the interview about how we will manage this.

For the IQ assessment part of the interview I would be grateful if you could be present but not take part.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of people who take part. This study has been reviewed and given favourable opinion by the Salomons Campus Ethics Panel.

Further information and contact details

If you would like to take part, or have any questions, please get in touch!

Email: s.lemmey487@canterbury.ac.uk

You can leave a message for me on a 24-hour voicemail phone line at (+44) 0333 011 7070. Please say that the message is for me (Suzie Lemmey) and leave a contact number so that I can get back to you.

You can also find out more about the background to the research through the following sources:

- Information on the ICF: <http://www.who.int/classifications/icf/en/>
- Details on current classification of athletes with ID: <http://www.inas.org/member-services/eligibility-and-classification>

Complaints

If you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions [(+44) 0333 011 7070].

If you are still unhappy and wish to complain you can contact:
Professor Paul Camic, Research Director

Salomons Centre for Applied Psychology, Broomhill Road, Tunbridge Wells. Kent. TN3 0TF.

Email: Paul.camic@canterbury.ac.uk

Tel: (+44) 03330 117 114



Deleted in
information
sheet for
supporters
of INAS
athletes






Appendix D: consent forms

**Consent form****Research with athletes with intellectual disabilities**



Researcher: Suzie Lemmey

Participant Identifier:

		Please initial box if you agree
	<p>I have read, or I have had read to me, the information sheet for the above study (dated 16/02/2017 v6)</p>	
	<p>I understand the information sheet for the above study (dated 16/02/2017 v6)</p>	

	<p>I know why you are doing this study.</p> <p>You have asked me if I have any questions.</p> <p>I have had any questions answered</p>	
	<p>I want to take part</p>	
	<p>I know that it's OK to stop at any time</p>	
	<p>I understand that Suzie may need to contact my sports organisation to get more information about me</p>	
	<p>I know that this information will be about what I'm great at and what I'm not so good at.</p>	

'sports organisation' amended to 'INAS' for INAS athletes

	It is OK for Suzie to find out this information	
	I agree to take part in this study	

Name of Participant Date Signature

Researcher Date Signature

Appendix E: INAS eligibility application

This has been removed from the electronic copy

Appendix F: Qualtrics questionnaire

Default Question Block

Thank you for taking the time to complete this questionnaire. This is the first stage of my major research project with Canterbury Christ Church University and INAS, looking at how we assess functional disability in athletes with intellectual disabilities.

The overall purpose of the research

The purpose of the research is to **explore the prevalence of physical and sensory disabilities in athletes with ID**. We are also exploring the relationship between these and intelligence (i.e. IQ). The reason for this is that, currently, there is only one competing class for athletes with ID at elite levels. This means that athletes with additional physical and/or sensory disabilities are often unable to compete at this level. We are working towards developing an additional competing class for athletes with ID, and hope that the information that we obtain in this research will be a step towards this goal.

About the questionnaire

The purpose of this questionnaire is to help us develop the assessment tool we will be using in the main research project. This questionnaire is based on the physical functioning section of the **International Classification of Functioning, Disability and Health (ICF)**. It is now a commonly used framework applied to understand a person's overall level of functioning, and is the accepted framework used by INAS.

Using a globally accepted framework and assessment has many advantages, but some disadvantages. The purpose of this preliminary research is to:

1. Find the most common issues upon which we need to focus
2. Eliminate questions that even people who know the person well would not be able to answer

Hence, there are more questions in this version than will be in the final version. We expect to do further work on the accessibility of this questionnaire.

How to complete the questionnaire

Please answer for **all people with intellectual disabilities (not just athletes) who you know well**. It will be difficult to be accurate, but answer the questions as best as you are able. To use this approach, we have to keep to the ICF terminology used. We will therefore also ask you to rate how easy the question was to answer.

The questionnaire should take 20-30 minutes. You do not need to complete it all in one sitting, as you can save your progress and come back to it another time.

Please submit your completed questionnaire by **Saturday 10th December**.

Further information and contact details

If you have any questions, please get in touch! Many thanks for your assistance with this project.

Email: s.lemmey487@canterbury.ac.uk

This project has ethical approval from Canterbury Christ Church University. However, if you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions [(+44) 0333 011 7070].

If you are still unhappy and wish to complain you can contact:
 Professor Paul Camic, Research Director
 Salomons Centre for Applied Psychology, Broomhill Road, Tunbridge Wells. Kent. TN3
 0TF.
 Email: Paul.camic@canterbury.ac.uk
 Tel: (+44) 03330 117 114

SENSES AND PAIN

In the people you know who have an intellectual disability, how common is it for you to have seen the following:

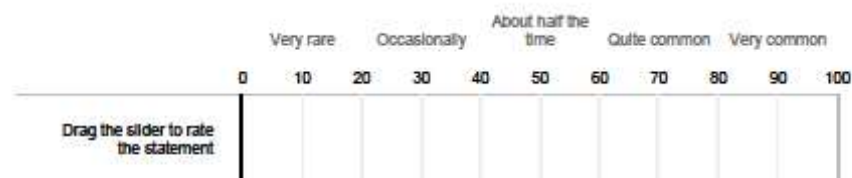
Q1a.

Problems with seeing

Problems with sensing the presence of light and/or seeing form, size, shape and colour.

Including: impairments such as myopia (short-sightedness), hypermetropia (long-sightedness), astigmatism, hemianopia (blindness over half the field of vision), colour-blindness, tunnel vision, central and peripheral scotoma (a partial loss of vision or blind spot in an otherwise normal visual field), diplopia (double vision), night blindness and impaired adaptability to light

Please answer this question for vision without glasses



Q1b. How easy was it to answer that question?

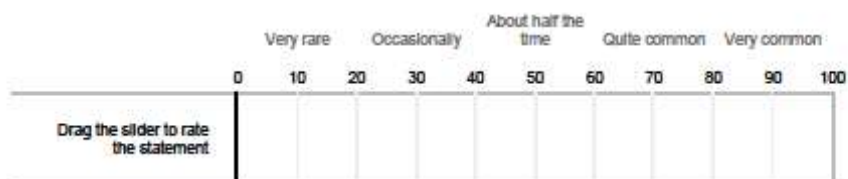
- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Q2a.

Problems with structures adjoining the eye

Problems with structures in and around the eye that facilitate seeing functions.

Including: the internal muscles of the eye, eyelid, external muscles of the eye, including voluntary and tracking movements and fixation of the eye, lachrymal glands, accommodation, pupillary reflex; impairments such as in nystagmus (constant uncontrolled movement of the eyes), xerophthalmia (abnormally dry eyes) and ptosis (drooping or falling of the upper eyelid).



Q2b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

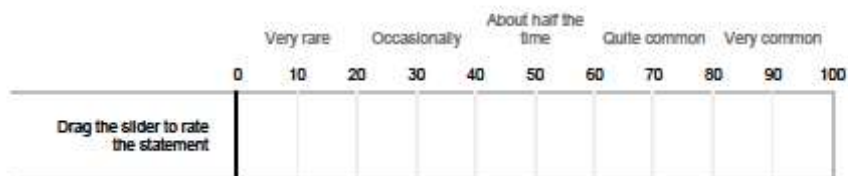
Q3a.

Problems associated with the eye and adjoining structures

Sensations of tired, dry and itching eye and related feelings.

Including: feelings of pressure behind the eye, of something in the eye when there is nothing there, eye strain, burning in the eye; eye irritation

Excluding: sensation of pain



Q3b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

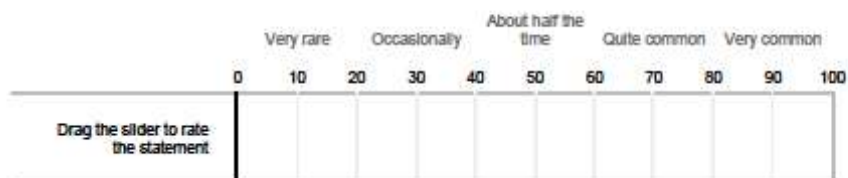
Q4a.

Problems with hearing

Problems relating to sensing the presence of sounds and discriminating the location, pitch, loudness and quality of sounds.

Including: auditory discrimination, localisation of sound source, lateralization of sound, speech discrimination; impairments such as deafness, hearing impairment and hearing loss.

Please answer this question for hearing without the use of, for example, a hearing aid.



Q4b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

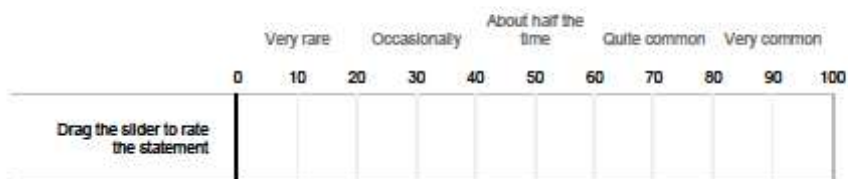
Q5a.

Problems with the vestibular system

Problems with the functions of the inner ear related to position, balance and movement.

Including: problems with position and positional sense; problems with balance of the body and movement

Excluding: sensations of ringing in ears, irritation in ear, pressure in the ear, or nausea associated with dizziness or vertigo



Q5b. How easy was it to answer that question?

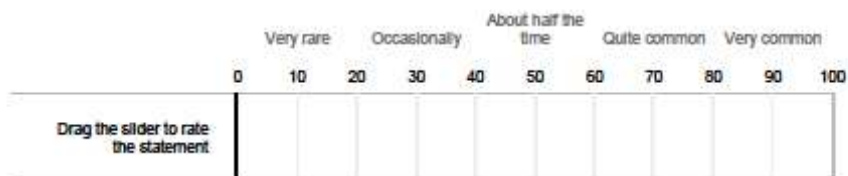
- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Q6a.

Problems associated with hearing and vestibular function

Sensations of dizziness, falling, tinnitus and vertigo.

Including: sensations of ringing in ears, irritation in ear, pressure in the ears, nausea associated with dizziness or vertigo.



Q6b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Q7a.

Problems with proprioceptive function

Problems with sensing the relative position of body parts.

Including: statesthesia (sensitivity for posture) and kinaesthesia (sensitivity to movement)

Excluding: vestibular functions; sensations related to muscles and movement functions (e.g. sensations of muscle stiffness and tightness of muscles, muscle spasm or constriction, and heaviness of muscles)



Q7b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

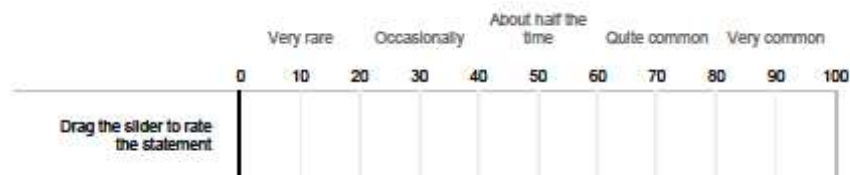
Q8a.

Problems related to touch

Problems with sensing surfaces and their texture or quality.

Including: problems with touching, feeling of touch; impairments such as numbness, anaesthesia, tingling, paraesthesia ('pins and needles') and hyperaesthesia (excessive physical sensitivity, especially of the skin)

Excluding: problems sensing temperature, vibration, pressure and noxious stimulus



Q8b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

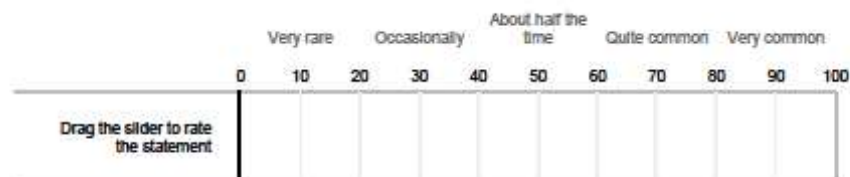
Q9a.

Problems related to sensing temperature and other stimuli

Problems with sensing temperature, vibration, pressure and unpleasant stimuli.

Including: sensitivity to temperature, vibration, shaking or oscillation (back and forth movement), superficial pressure, deep pressure, burning sensation or sensitivity to an unpleasant or harmful stimulus

Excluding: sensitivity to touch; sensation of pain



Q9b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

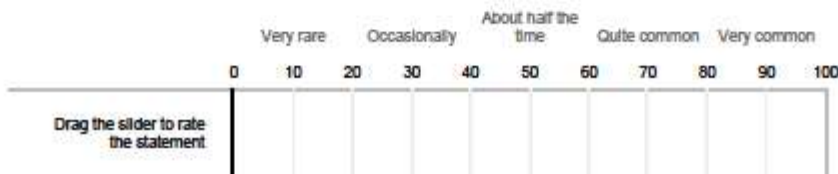
Extremely difficult

Q10a.

Sensations of pain

Unpleasant feelings indicating potential or actual damage to some body structure.

Including: sensations of generalized or localized pain in one or more body part, pain in an area of skin, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia (muscle pain), analgesia (inability to feel pain) and hyperalgesia (abnormally heightened sensitivity to pain)



Q10b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Are there any specific problems with:

- seeing
- the eye
- hearing
- the inner ear
- sensing the position of the body
- touch
- pain

that are common in people with intellectual disabilities? Or are there additional, related problems that were not covered? If so, please comment below:

THE HEART, LUNGS AND IMMUNE SYSTEM

In the people you know who have an intellectual disability, how common is it for you to have seen the following:

Q11a. **Problems with the heart**

Problems with the heart pumping blood around the body.

Including: problems with heart rate and rhythm; the heart muscles; the heart valves; impairments such as tachycardia (abnormally high heart rate), bradycardia (abnormally slow heart rate) and irregular heart beat and as in heart failure, cardiomyopathy (chronic disease of the heart muscle), myocarditis (inflammation and damage of the heart muscle) and coronary insufficiency (insufficient blood flow through one or more arteries in the heart)

Excluding: problems related to the blood vessels, blood pressure, or exercise tolerance



Q11b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

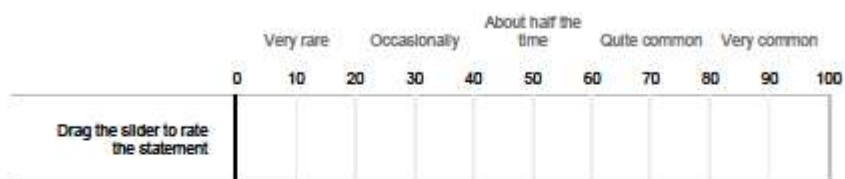
Q12a.

Problems with blood vessels

Problems related to the ability to transport blood throughout the body.

Including: problems with the arteries, capillaries and veins; constriction or dilatation of blood vessels; valves of veins; impairments such as in blockage or constriction of arteries; atherosclerosis (a disease of the arteries characterized by the deposition of fatty material on their inner wall), arteriosclerosis (the thickening and hardening of the walls of the arteries), thromboembolism (obstruction of a blood vessel by a blood clot) and varicose veins

Excluding: problems related to the heart; blood pressure; blood and bone marrow; or exercise tolerance



Q12b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult

Q14b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

Q15a.

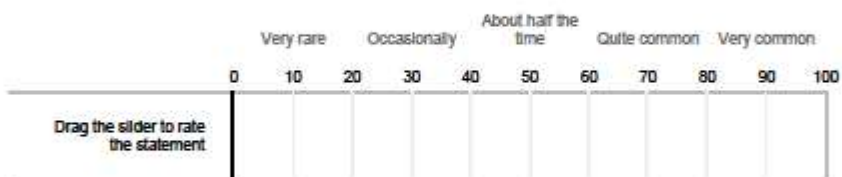
Problems with respiration

Problems with inhaling air into the lungs, the exchange of gases between air and blood, and exhaling air.

Including: problems with respiration rate, rhythm and depth; impairments such as apnoea (temporary cessation of breathing, especially during sleep), hyperventilation, irregular respiration, paradoxical respiration

breathing in which all or part of the chest wall moves in during inhalation and out during exhalation) and bronchial spasm (sudden constriction of the muscles in the walls of the bronchioles) and as in pulmonary emphysema (a condition in which the air sacs of the lungs are damaged and enlarged, causing breathlessness.)

Excluding: problems with the respiratory muscles; additional respiratory functions; or exercise tolerance



Q15b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

Q16a.

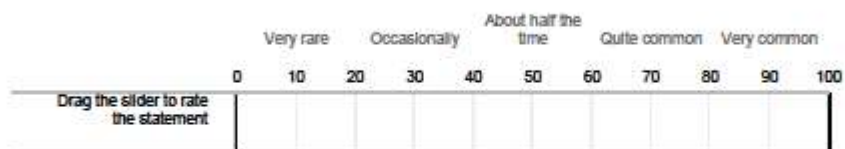
Problems with the respiratory muscles

Problems with the muscles involved in breathing.

Including: problems with the thoracic respiratory muscles; diaphragm; accessory respiratory muscles

Excluding: problems with respiration; additional respiratory problems; or exercise tolerance





Q10b. How easy was it to answer that question?

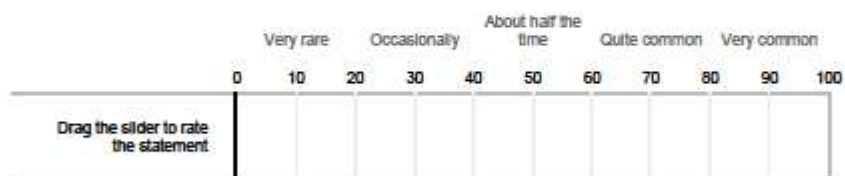
- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

Q17a.

Additional respiratory issues

Additional problems related to breathing, such as coughing, sneezing and yawning.

Including: mouth breathing



Q17b. How easy was it to answer that question?

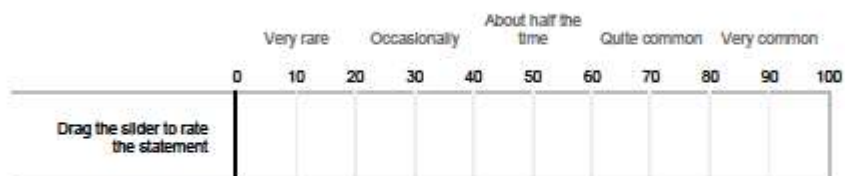
- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

Q18a. **Exercise tolerance**

Issues related to respiratory and cardiovascular capacity required for enduring physical exertion.

Including: physical endurance, aerobic capacity, stamina and fatiguability

Excluding: problems with the cardiovascular system; haematological system; respiration; respiratory muscles; additional respiratory issues



Q18b. How easy was it to answer that question?

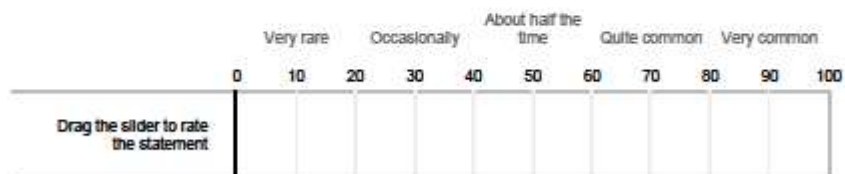
- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Q19a. **Sensations associated with cardiovascular and respiratory functions**

Sensations such as missing a heart beat, palpitation and shortness of breath.

Including: sensations of tightness of chest, feelings of irregular beat, dyspnoea (shortness of breath or breathlessness), air hunger, choking, gagging and wheezing

Excluding: sensations of pain



Q19b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Are there any specific problems with:

- the heart
- blood vessels
- blood pressure
- immune system
- respiration

- muscles involved in breathing
- respiratory issues
- exercise tolerance
- sensations involved with cardiovascular and respiratory functions

that are common in people with intellectual disabilities? Or are there additional, related problems that were not covered? If so, please comment below:

MOVEMENT AND MOBILITY

In the people you know who have an intellectual disability, how common is it for you to have seen the following:

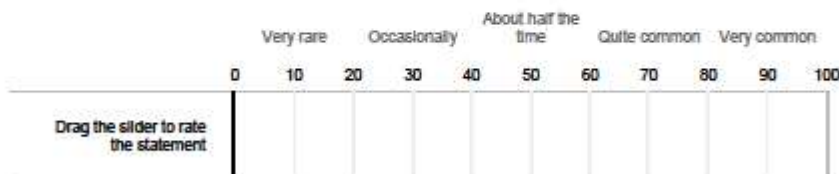
Q20a.

Problems with joint mobility

Problems with the range and ease of movement of a joint.

Including: problems with the mobility of a single or several joints, vertebral, shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet; mobility of joints in general; impairments such as in hypermobility of joints, frozen joints, frozen shoulder, arthritis

Excluding: stability of joints; control of voluntary movement



Q20b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

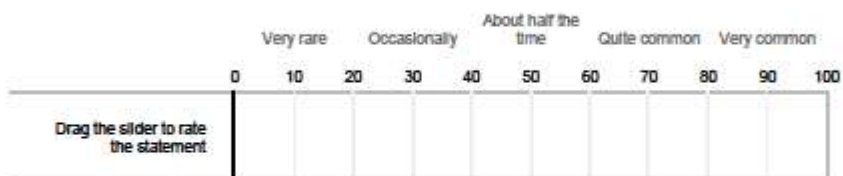
Q21a.

Problems with the stability of joints

Problems with the maintenance of structural integrity of the joints.

Including: problems with the stability of a single joint, several joints, and joints in general; impairments such as in unstable shoulder joints, dislocation of a joint, dislocation of shoulder and hip

Excluding: mobility of joints



Q21b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

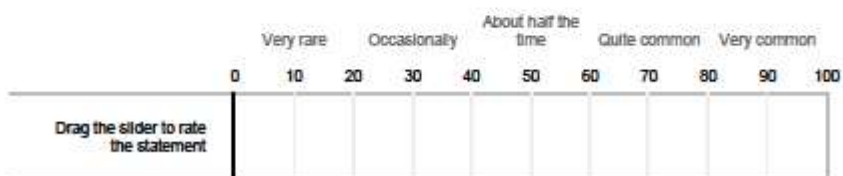
Q22a.

Problems with the mobility of bones

Problems with the range and ease of movement of the scapula (shoulder blade), pelvis, carpal (wrist) and tarsal (foot) bones.

Including: impairments such as frozen scapula and frozen pelvis

Excluding: mobility of joints



Q22b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

Q23a.

Problems with muscle power

Problems related to the force generated by the contraction of a muscle or muscle groups.

Including: problems associated with the power of specific muscles and muscle groups, muscles of one limb, one side of the body, the lower half of the body, all limbs, the trunk and the body as a whole; impairments

such as weakness of small muscles in feet and hands, muscle paresis (weakness), muscle paralysis, monoplegia (paralysis restricted to one limb or region of the body), hemiplegia (paralysis of one side of the body), paraplegia (complete or incomplete paralysis affecting the legs and possibly also the trunk, but not the arms), quadriplegia (partial or total loss of use of all four limbs and torso) and akinetic mutism (unable to speak or move)

Excluding: structures adjoining the eye; muscle tone; muscle endurance



Q23b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

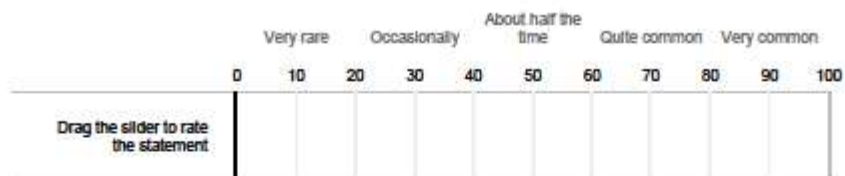
Q24a.

Problems with muscle tone

Problems related to the tension present in the resting muscles and the resistance offered when trying to move the muscles.

Including: problems associated with the tension of isolated muscles and muscle groups, muscles of one limb, one side of the body and the lower half of the body, muscles of all limbs, muscles of the trunk, and all muscles of the body; impairments such as hypotonia (decreased muscle tone), hypertonia (increased muscle tone) and muscle spasticity (tight or stiff muscles and an inability to control those muscles)

Excluding: muscle power; muscle endurance



Q24b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult

Extremely difficult

Q25a.

Problems with muscle endurance

Problems related to sustaining muscle contraction for the required period of time.

Including: problems associated with sustaining muscle contraction for isolated muscles and muscle groups, and all muscles of the body; Impairments such as in myasthenia gravis (a rare long-term condition that causes certain muscles in the body to become weak)

Excluding: exercise tolerance; muscle power; muscle tone



Q25b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Q26a.

Problems related to motor reflexes

Problems with involuntary contraction of muscles automatically induced by specific stimuli.

Including: problems with stretch motor reflex, automatic local joint reflex, reflexes generated by unpleasant stimuli and other external stimuli; withdrawal reflex, biceps (upper arm) reflex, radius (forearm) reflex, quadriceps (thigh) reflex, patellar (knee) reflex, ankle reflex



Q26b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
-

Q28b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

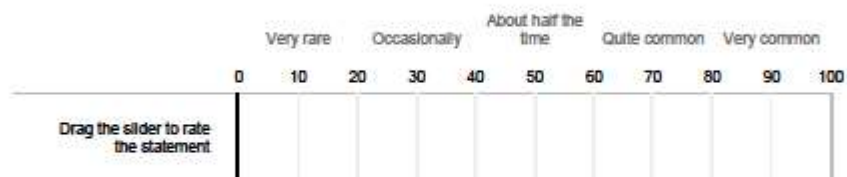
Q29a.

Problems related to involuntary movement

Problems with unintentional, non- or semi-purposive involuntary contractions of a muscle or group of muscles.

Including: involuntary contractions of muscles; impairments such as tremors, tics, mannerisms, stereotypies (repetitive or ritualistic movement, posture, or utterance), motor perseveration (uncontrolled repetition or continuation of a response), chorea (involuntary jerky movements), athetosis (involuntary writhing movements), vocal tics, dystonic movements (involuntary muscle contractions that cause slow repetitive movements or abnormal postures) and dyskinesia (involuntary muscle movements)

Excluding: control of voluntary movement; gait pattern



Q29b. How easy was it to answer that question?

- Extremely easy
 Somewhat easy
 Neither easy nor difficult
 Somewhat difficult
 Extremely difficult

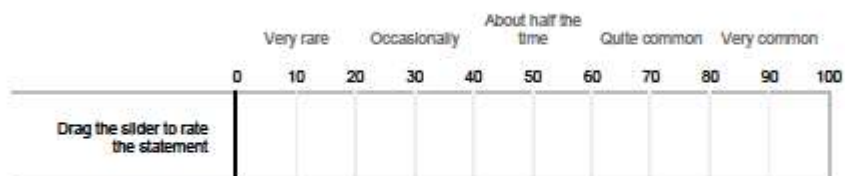
Q30a.

Problems related to gait pattern

Problems with movement associated with walking, running or other whole body movements.

Including: walking patterns and running patterns; impairments such as spastic gait (walking stiffly, dragging the feet), hemiplegic gait (gait resulting from weakness/paralysis on one side of the body), paraplegic gait (gait resulting from weakness/paralysis in the lower limbs), asymmetric gait (limbs move together), limping and stiff gait pattern

Excluding: muscle power; muscle tone; control of voluntary movement; involuntary movement



Q30b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

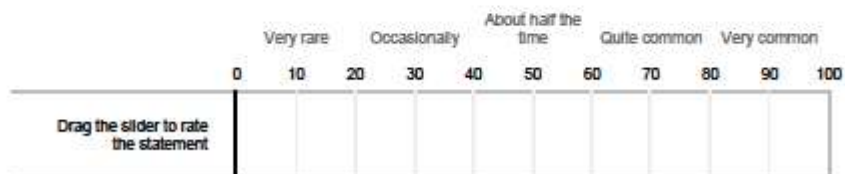
Q31a.

Sensations related to muscles and movement functions

Sensations associated with the muscles or muscle groups of the body and their movement.

Including: sensations of muscle stiffness and tightness of muscles, muscle spasm or constriction, and heaviness of muscles

Excluding: sensation of pain



Q31b. How easy was it to answer that question?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Are there any specific problems with:

- joint mobility
- joint stability
- mobility of bones
- muscle power

- muscle tone
- muscle endurance
- motor reflexes
- involuntary movement reactions
- control of voluntary movement
- involuntary movement
- gait
- muscles and movement functions

that are common in people with intellectual disabilities? Or are there additional, related problems that were not covered? If so, please comment below:

Q32. If there are any other physical issues or health issues that, in your experience, you feel are common for people with intellectual disabilities, please expand on this below:

Q33. Following on from the previous question, do you think these issues have an impact on sport performance? If so, please expand on this below:

Q34. How helpful did you find the additional information in *italics* (e.g. Q1a - *Including: impairments such as myopia (short-sightedness), hypermetropia (long-sightedness), astigmatism, etc.*)

Q35. Have you any other comments about how to make the questionnaire easier to complete?

Q36. If you have any other comments please write them here

. Many thanks for your time and help.

We will be modifying the questionnaire based on your feedback, including adapting the language used to make sure that it is accessible to people with intellectual disabilities. We would be very grateful for your comments on this, and will be back in touch to ask you to review it. If you would rather not take part in this second stage please just get in touch.

Appendix G: ICF-based questionnaire



The ICF-based Questionnaire

PART ONE

I'm going to start by asking some questions about you. You can ask your parent/carer/coach for help to answer the questions, if you need to.

- i. What is your gender?**
Male/Female/Other
[if hesitation: Would you say you are a man, a woman, or something else?]
- ii. What is your date of birth?**
- iii. What is your nationality?**
- iv. What is your ethnic group/background?**
[if hesitation: "Sometimes people are unsure about this question". Use a famous person or, if you're happy to, yourself as an example]
- v. How many years have you been competing as an athlete (in any sport)?**
- vi. How many years have you been competing in this sport?**

vii. Do you compete in any other sports?

viii. Do you have any problems with your health at the moment?

[If yes] What are your main problems at the moment?

ix. Are you taking any medication, either prescribed or over the counter?

[If yes] What are they?

x. Do you use any assistive device, such as glasses, hearing aid, wheelchair etc?

[If yes] What are they?

Can you play sport when wearing your [insert device]?

xi. Do you have Down Syndrome?

[If yes] Do you know which type?

Trisomy 21 (nondisjunction) / Translocation /

Mosaicism / Don't know

PART TWO

Now I'm going to ask you some questions about your physical health.

These questions are taken from a tool made by the World Health Organisation. So some of the language that's used is a bit difficult

or confusing. I can give you more information to help you answer the question if you need it, just ask! Your parent/coach/carer can also help to answer the questions.

You might not see these things as much of a problem. Or you might not think that they affect your day-to-day life very much. So it might be useful when answering the questions to think about someone else around your age that you know without the problem, to see if there is any difference.

This section is quite long. Please let me know if you'd like to stop or have a break.

Q1a Do you have problems with consciousness?

This means problems with being aware, alert and awake.

This includes loss of consciousness, such as blackouts, or fainting

[Including: functions of the state, continuity and quality of consciousness]

Q1b If yes, how much of a problem is this?

Mild Moderate Severe Complete

[always illustrate this question using the scale at the end]

Q2a Do you have problems with energy and drive?

This includes things like your energy level, motivation, appetite, craving (including craving for substances, like alcohol), and impulse control

[Problems with the physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner.]

Q2b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Now I'm going to ask you some questions about SENSES AND PAIN

Please answer this question for how you see without glasses, if you wear them

Q3a. Do you have problems with seeing things?

[Problems with sensing the presence of light and/or seeing form, size, shape and colour.

Including: impairments such as myopia (short-sightedness), hypermetropia (long-sightedness), astigmatism, hemianopia (blindness over half the field of vision), colour-blindness, tunnel vision, central and peripheral scotoma (a partial loss of vision or blind spot in an otherwise normal visual field), diplopia (double vision), night blindness and impaired adaptability to light]

Q3b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q4a. Do you have problems with the structures adjoining the eye?

This means problems with the structures in and around the eye that help you to see, such as the muscles in the eye, and the eyelid.

[Including: external muscles of the eye, including voluntary and tracking movements and fixation of the eye, lachrymal glands, accommodation, pupillary reflex; impairments such as in nystagmus (constant uncontrolled movement of the eyes), xerophthalmia (abnormally dry eyes) and ptosis (drooping or falling of the upper eyelid).]

Q4b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q5a. Do you have problems related to your eyes and adjoining structures?

This means sensations of tired, dry and itching eyes and related feelings.

[Including: feelings of pressure behind the eye, of something in the eye when there is nothing there, eye strain, burning in the eye; eye irritation]

Q5b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Please answer this question for hearing without the use of, for example, a hearing aid, if you use one.

Q6a. Do you have problems with hearing sounds?

[Problems relating to sensing the presence of sounds and telling the different location, pitch, loudness and quality of sounds.

Including: auditory discrimination, localisation of sound source, lateralization of sound, speech discrimination; impairments such as deafness, hearing impairment and hearing loss.]

Q6b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q7a. Do you have problems with the vestibular system?

This means problems with position, balance and movement.

[Related to functions of the inner ear. Including: problems with position and positional sense; problems with balance of the body and movement]

Q7b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q8a. Do you have problems related to hearing and vestibular function?

This means sensations of dizziness, falling, tinnitus (ringing in ears) and vertigo.

[Including: sensations of ringing in ears, irritation in ear, pressure in the ears, nausea associated with dizziness or vertigo.]

Q8b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q9a. Do you have problems with proprioceptive function?

This means problems with sensing the relative position of body parts, without looking. For example, sitting here and knowing where your legs and feet are, without looking.

[Including: statesthesia (also known as joint position sense: the ability to know where your joints are when you have your eyes closed) and kinaesthesia (awareness of position, weight, tension and movement)]

Q9b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q10a. Do you have problems related to touch?

This means problems with sensing surfaces and their texture or quality. For example, being able to tell what this table feels like.

[Including: problems with touching, feeling of touch; impairments such as numbness, anaesthesia (temporary loss of sensation), tingling, **paraesthesia** ('pins and needles') and **hyperaesthesia** (excessive physical sensitivity, especially of the skin)]

Q10b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q11a. Do you have problems related to sensing temperature, vibration, and pressure?

[Including: **sensitivity to** temperature, vibration, shaking or oscillation (swaying), superficial (slight) pressure, deep pressure, burning sensation or sensitivity to an unpleasant or harmful stimulus]

Q11b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q12a. Do you have sensations of pain?

This includes problems such as muscle pain, inability to feel pain, and being much more sensitive to pain than other people

[Unpleasant feelings indicating potential or actual damage to some body structure.

Including: myalgia (muscle pain), analgesia (inability to feel pain) and hyperalgesia (abnormally heightened sensitivity to pain), sensations of generalized or localized pain in one or more body part, pain in an area of skin, stabbing pain, burning pain, dull pain, aching pain]

Q12b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Now I'm going to ask you some questions about your HEART, LUNGS AND IMMUNE SYSTEM

Q13a. Do you have problems with your heart?

[Problems with the heart pumping blood around the body.

Including: problems with heart rate and rhythm; the heart muscles; the heart valves; impairments such as tachycardia (abnormally high heart rate), bradycardia (abnormally slow heart rate) and irregular heart beat

and as in heart failure, cardiomyopathy (chronic disease of the heart muscle), myocarditis (inflammation and damage of the heart muscle) and coronary insufficiency (insufficient blood flow through one or more arteries in the heart)]

Q13b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q14a. Do you have problems with your blood vessels?

This means problems with moving blood around the body.

[Including: problems with the arteries, capillaries and veins (the tubes that transport blood around the body); constriction (tightening) or dilatation (widening) of blood vessels; valves of veins; impairments such as in blockage or constriction of arteries; atherosclerosis (a disease of the arteries in which fatty material is left on their inner wall), arteriosclerosis (the thickening and hardening of the walls of the arteries), thromboembolism (obstruction of a blood vessel by a blood clot) and **varicose veins** (swollen and enlarged veins)]

Q14b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q15a. Do you have problems with blood pressure?

[This is what doctors look at when they put a cuff around your arm.

This means problems with keeping up a steady flow of blood around your body.

Including: problems with maintaining blood pressure; increased and decreased blood pressure; impairments such as in hypotension (abnormally low blood pressure), hypertension (abnormally high blood pressure) and postural hypotension (a drop in blood pressure after standing for at least one minute)]

Q15b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q16a. Do you have problems with your immune system?

This means problems related to protecting the body against things like infections.

This includes allergic reactions.

[Including: problems with the immune response (specific and non-specific); hypersensitivity reactions; lymphatic vessels and nodes; cell-mediated immunity, antibody-mediated immunity; response to immunization;

impairments such as in autoimmunity (abnormal immune response to a normal body part), lymphadenitis (inflammation of the lymph nodes) and lymphoedema (localized fluid retention and tissue swelling caused by a compromised lymphatic system)]

Q16b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q17a. Do you have problems with breathing?

[Problems with inhaling air into the lungs, the exchange of gases between air and blood, and exhaling air.

Including: problems with respiration rate, rhythm and depth; impairments such as apnoea (temporarily stopping breathing, especially during sleep), hyperventilation, irregular respiration, paradoxical respiration (breathing in which all or part of the chest wall moves in during inhalation and out during exhalation) and bronchial spasm (sudden constriction of the muscles in the walls of the bronchioles) and as in pulmonary emphysema (a condition in which the air sacs of the lungs are damaged and enlarged, causing breathlessness.)]

Q18b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q18a. Do you have problems with the muscles involved in breathing?

[Including: problems with the thoracic respiratory muscles; diaphragm; accessory respiratory muscles]

Q18b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q19a. Do you have additional breathing issues?

This means additional problems related to breathing, such as coughing, sneezing, yawning and mouth breathing

Q19b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q20a. Do you have problems with exercise tolerance?

This means issues related to breathing and your heart which allow you to exercise for a long time.

This includes: your body's ability to take in and use oxygen to do well in sport, and if you get tired or lose strength easily

Q20b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q21a. Do you have problems with sensations related to your heart and breathing?

This means sensations such as missing a heart beat, feelings of very quick or irregular heartbeat, and **shortness of breath**.

[Including: sensations of tightness of chest, palpitations, dyspnoea (shortness of breath or breathlessness), air hunger, choking, gagging and wheezing]

Q21b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q22a Do you have problems with keeping a healthy body weight?

[This includes: maintenance of acceptable **Body Mass Index (BMI)**; impairments such as underweight, cachexia (weakness and wasting of the body due to severe chronic illness), wasting, overweight, emaciation (being abnormally thin or weak) and **such as in primary and secondary obesity**]

Q22b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Now I'm going to ask you some questions about MOVEMENT AND MOBILITY

Q23a. Do you have problems with moving your joints?

This includes problems such as in **hypermobility** of joints (like your wrist moving back too far), frozen joints, and **arthritis**

[This means problems with the range and ease of movement of a joint.

This includes: problems with the mobility of a single or several joints; mobility of joints in general.

joints include: vertebral (spine), shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet]

Q23b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q24a. Do you have problems with the stability of joints?

This means problems with the muscles and ligaments around your joints, that might mean that your joints dislocate, or you get a lot of injuries to your joints.

[This includes: problems with the stability of a single joint, several joints, and joints in general; impairments such as in unstable shoulder joints, **dislocation** of a joint, dislocation of shoulder and hip]

Q24b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q25a. Do you have problems with the mobility of bones?

This means problems with the range of movement, and how easy it is to move, your shoulder blade, pelvis, and bones in the wrist and foot

[Including: impairments such as frozen scapula and frozen pelvis]

Q25b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q26a. Do you have problems with muscle power?

Examples of muscular power include throwing a punch, jumping over a hurdle, or swinging a bat.

This includes muscle weakness and muscle paralysis

[This means problems related to the force generated by the contraction of a muscle or muscle groups.

Including: problems associated with the power of specific muscles and muscle groups, muscles of one limb, one side of the body, the lower half of the body, all limbs, the trunk and the body as a whole;

impairments such as weakness of small muscles in feet and hands, monoplegia (paralysis restricted to one limb or region of the body), hemiplegia (paralysis of one side of the body), paraplegia (complete or incomplete paralysis affecting the legs and possibly also the trunk, but not the arms), quadriplegia (partial or total loss of use of all four limbs and torso)]

Q26b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q27a. Do you have problems with muscle tone?

If you have high muscle tone, this means that your muscles are tight and tense, even when you're not doing anything. If you have low muscle tone, you don't have enough tension in your muscles when you're resting, and muscles might feel 'floppy'.

[For example², if you had high muscle tone, you would have to concentrate very hard to reach out to grab a drink. It would take a lot of effort, and your movement might be jerky. If you have low muscle tone, you might need to use a bit extra momentum to grab a drink, maybe by flinging your arm out! You might then use too much oomph at first (to overcome the lack of "tension" in your muscles) with the result that the drink sloshes out!

² <http://www.ot-mom-learning-activities.com/muscle-tone.html>

Muscle tone means problems related to the tension present in the resting muscles and the resistance offered when trying to move the muscles.

This includes muscle spasticity (tight or stiff muscles and an inability to control those muscles)

Including: problems associated with the tension of isolated muscles and muscle groups, muscles of one limb, one side of the body and the lower half of the body, muscles of all limbs, muscles of the trunk, and all muscles of the body; impairments such as hypotonia (decreased muscle tone), hypertonia (increased muscle tone)]

Q27b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q28a. Do you have problems with muscle endurance?

This means problems related to your muscles keeping going without getting tired, like in doing sit ups, lifting weights, or in running or swimming.

[Including: problems associated with sustaining muscle contraction for isolated muscles and muscle groups, and all muscles of the body; impairments such as in myasthenia gravis (a rare long-term condition that causes certain muscles in the body to become weak)]

Q28b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q29a. Do you have problems related to motor reflexes?

For example: reacting when you touch something hot. This means problems with your muscles working automatically, without you thinking about it, in reaction to something.

[Including: problems with stretch motor reflex, automatic local joint reflex, reflexes generated by unpleasant stimuli and other external stimuli; withdrawal reflex, biceps (upper arm) reflex, radius (forearm) reflex, quadriceps (thigh) reflex, patellar (knee) reflex, ankle reflex]

Q29b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q30a. Do you have problems related to involuntary movement reactions?

For example: when you step into the road and notice a car is coming, and you're able to jump back without thinking about it; or when you lose your balance and have to right yourself so you don't fall over.

[This means problems with involuntary contractions of large muscles or the whole body induced by body position, balance and threatening stimuli.

Including: problems with postural reactions, righting reactions, body adjustment reactions, balance reactions, supporting reactions, defensive reactions]

Q30b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q31a. Do you have problems related to control of voluntary movement?

This means problems with control over and **coordination** of voluntary movements.

This includes hand-eye coordination

[Including: problems of control of simple voluntary movements and of complex voluntary movements, coordination of voluntary movements, supportive functions of arm or leg, right left motor coordination, eye foot coordination; impairments such as control and coordination problems, e.g. dysdiadochokinesia (impaired ability to perform rapid, alternating movements)]

Q31b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q31c. Do you have problems related to control of complex voluntary movements?

This means problems with control over and coordination of **complex** voluntary movements. This is sometimes called fine motor control. For example, movements of the hands and fingers, like when holding a pen or doing up buttons.

Q31d If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q32a. Do you have problems related to involuntary movement?

This includes tremors, tics (like twitching or making a noise without meaning to) or other unusual movements

[This means problems with unintentional, non- or semi-purposive involuntary contractions of a muscle or group of muscles.

Including: involuntary contractions of muscles; impairments such as mannerisms, stereotypies (repetitive or ritualistic movement, posture, or utterance), motor perseveration (uncontrolled repetition or continuation of a response), chorea (involuntary jerky movements), athetosis (involuntary writhing movements), vocal tics, dystonic movements (involuntary muscle contractions that cause slow repetitive movements or abnormal postures) and dyskinesia (involuntary muscle movements)]

Q32b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Q33a. Do you have problems related to gait pattern?

This means problems with movements when you walk or run.

[Including: walking patterns and running patterns; impairments such as spastic gait (walking stiffly, dragging the feet), hemiplegic gait (gait resulting from weakness/paralysis on one side of the body), paraplegic gait (gait resulting from weakness/paralysis in the lower limbs), asymmetric gait (limbs move together), limping and stiff gait pattern]

Q33b If yes, how much of a problem is this?

Mild Moderate Severe Complete

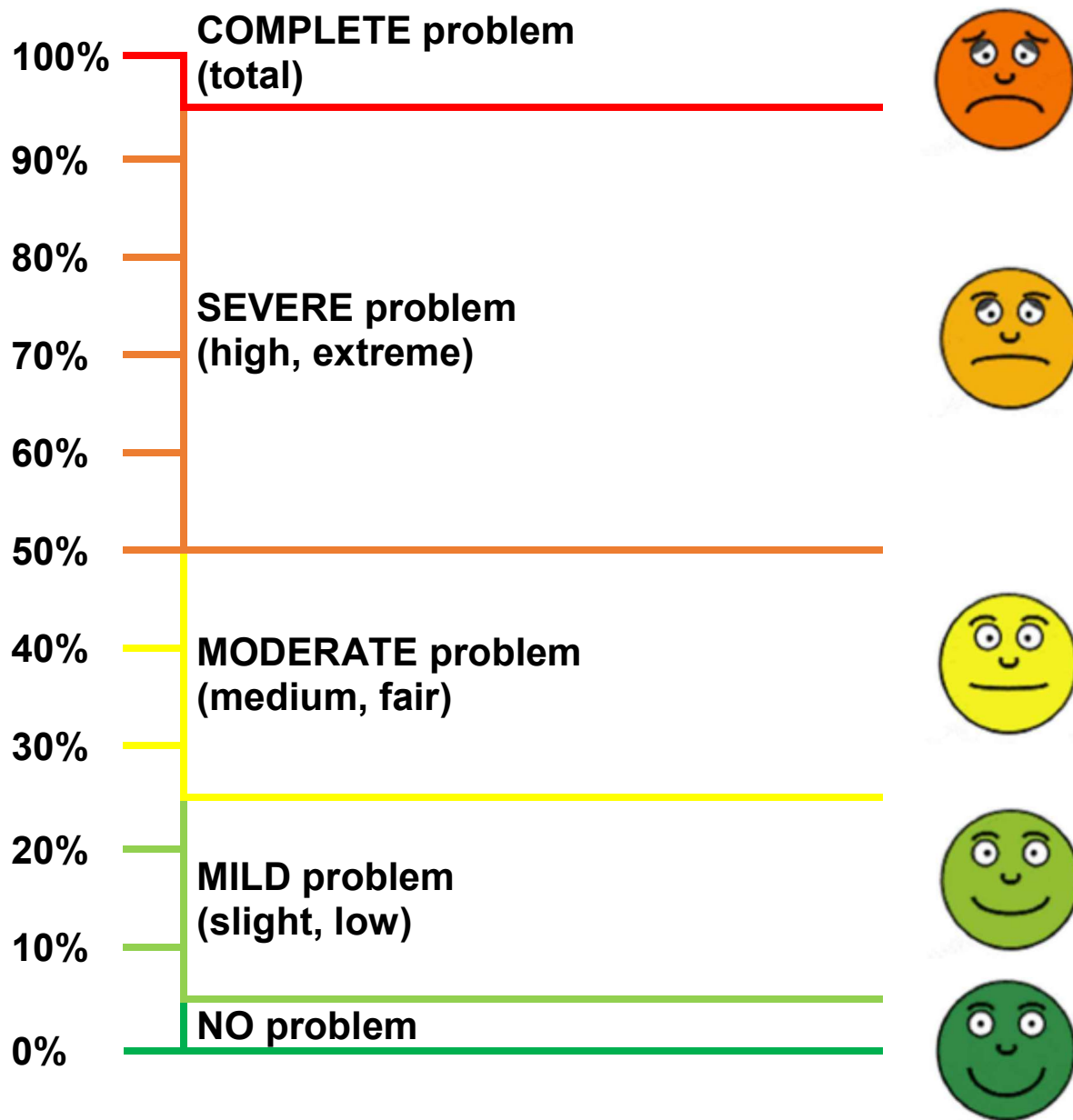
Q34a. Do you have sensations related to muscles and movement functions?

This includes sensations of muscle stiffness and tightness of muscles, muscle spasm or constriction, and heaviness of muscles.

Q34b If yes, how much of a problem is this?

Mild Moderate Severe Complete

Appendix H: Scale



Appendix I: Post-interview questionnaire**Post-interview questionnaire**

1. Do you have a diagnosis of epilepsy?

Yes No Don't know

2. Do you have a diagnosis of Autism, Asperger's Syndrome or Autism Spectrum Disorder (ASD)?

Yes No Don't know

3. Do you have a diagnosis of Cerebral Palsy?

Yes No Don't know

4. What did you think about the length of the ICF interview?

Too long

Long, but OK

Just right

Too short

5. Did you understand the questions that were asked?

Yes, all of them

Yes, most of them

Yes, some of them

No

If No, which ones?

6. Did you think the questions applied to you?

Yes

No

Is there anything that could have been explained more? If so what?

Is there anything I should have asked about that didn't come up today?

Any other comments?

Thank you!

Appendix J: Guidance for event organisers



Physical health in athletes with intellectual disabilities: **Information about the research for event organisers**

Hello. My name is Suzie Lemmey and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like your help in recruiting athletes with intellectual disabilities (ID) to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you.

Please feel free to talk to others about the study if you wish. Please also **read the information sheet for athletes** for further details.

What is the purpose of the study?

The purpose of the study is to **explore physical and sensory abilities in athletes with ID**. We are also exploring the relationship between these and intelligence (i.e. IQ). The reason for this is that, currently, there is only one competing class for athletes with ID at elite levels. This means that athletes with additional physical and/or sensory disabilities are often unable to compete at this level. We are working towards developing an additional competing class for athletes with ID, and hope that the information that we obtain in this research will be a step towards this goal. We also think that the findings may have implications for how ID is viewed more globally, i.e. as more than just IQ.

Why have I been contacted?

We are hoping to interview athletes with intellectual disabilities at a range of different sporting events in 2017, including regional events, events organised by the Special Olympics, and those for elite athletes organised by The International Association of Sport for para-athletes with an intellectual disability (INAS). As the organiser of **XXXevent** we would be very grateful for your agreement to allow us to interview athletes at your event, and your assistance to undertake interviews at the event.

What will I have to do?

1. Before the event

We would be grateful for your help in letting the athletes competing at your event know about the research. This could be by putting the information sheets on your event registration website and/or including them in the registration pack. It would also be useful to speak to you before the event to think through logistics (for example when I should arrive).

2. At the event

We would be grateful for your help in organising a private, quiet space large enough for four people (myself, the athlete, someone who knows the athlete, and a translator, if needed). It would be very helpful if I could attend any welcome meetings to let people know about why I'm there. It would also be useful if I could display posters and the information sheet at the event to let people know about the research (see attached example).

3. After the event

You won't need to do anything else after the event! However, we will send you a short report to let you know about the findings of the research.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of people who take part. This study has been reviewed and given favourable opinion by the Salomons Campus Ethics Panel.

Who is funding the study?

The study will be funded jointly by Canterbury Christ Church University and INAS. We will not be asking for any financial support from individual event organisers.

Further information and contact details

If you would like to take part, or have any questions, please get in touch!

Email: s.lemmey487@canterbury.ac.uk

You can leave a message for me on a 24-hour voicemail phone line at (+44) 0333 011 7070. Please say that the message is for me (Suzie Lemmey) and leave a contact number so that I can get back to you.

Complaints

If you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions [(+44) 0333 011 7070].

If you are still unhappy and wish to complain you can contact:
Professor Paul Camic, Research Director

Salomons Centre for Applied Psychology, Broomhill Road, Tunbridge Wells. Kent. TN3 0TF.

Email: Paul.camic@canterbury.ac.uk

Tel: (+44) 03330 117 114

Appendix K: Confidentiality statement



Confidentiality Statement for Persons Undertaking Research Project Interviews

Project title: What can athletes with intellectual disability (ID) tell us about taxonomic frameworks applied to ID?

Researcher's names: Suzie Lemmey and Professor Jan Burns

The data that you are gathering via interviews is part of the above research project. This data may be of a personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University. Signing this form means you agree not to disclose any data to others, and not to reveal any identifying names, place-names or other information to any person other than the researcher named above. You agree to keep the data in a secure place where it cannot be accessed by other people, and to show your data only to the relevant individual who is involved in the research project, i.e. the researcher named above.

You will also follow any instructions given to you by the researcher about how to disguise the names of people and places within the data, so that the data will not contain such names of people and places.

Following completion of the data collection you will not retain any of the data or materials, in any form. You will pass all electronic data back to the researcher and erase any material remaining on your computer hard drive or other electronic medium on which it has been held. Any hard copies of the data will be destroyed.

You agree that if you find that anyone that you interview is known to you, you will stop the interview immediately and inform the participant that you will not be able to continue with the interview. The interview may be continued by a trained colleague, if available.

Declaration

I agree that:

1. I will discuss the content of the data only with the researchers named on the previous page.
2. I will keep all data in a secure place where they cannot be found by others.
3. I will treat the data as confidential information.
4. I will agree with the researcher how to disguise names of people and places within the data.
5. I will not retain any written or electronic material following completion of data collection.
6. If the person being interviewed is known to me I will not undertake the interview.

I agree to act according to the above constraints

Your name _____

Signature _____

Date _____

Occasionally, the content of the interview may be distressing to hear. If you should find it upsetting, please speak to the researcher.

Appendix L: Training resources for additional researchers



ICF-based interview with athletes with learning disabilities: Researcher protocol

Please ensure that you have discussed and completed the confidentiality agreement for additional researchers.

This document has been designed as a guide to aid additional researchers in completing interviews with athletes with learning disabilities. This is part of a project being conducted by Suzie Lemmey at Canterbury Christ Church University. It will be supplemented with further training, in person or via Skype. If you have any questions following this, or any suggestions for further inclusions in this document or the FAQ, please contact Suzie at s.lemmey487@canterbury.ac.uk

Approaching people at events

- Introduce yourself
- Ask people if they have time to hear about the research
- Briefly introduce the research (familiarise yourself with the FAQ section in **Appendix A**)
 - Give them an idea of how long it will take (**up to 30 minutes for INAS athletes, 60 minutes for other athletes**: emphasise that this can be broken up)
- Give people the information sheets for athletes and informants.
- **Find out:**
 - If they are 18 or older (they need to be 18 or older to be eligible to take part)
 - If they compete with INAS. If they do, the WASI-II probably does not need to be conducted. Please ask Suzie to confirm this.
 - If not at an event, if they have taken part in an event in the last 12 months (also an eligibility criteria)
 - Who could join the athlete in the interview. This should be someone who knows them, and their physical health, well. This informant should receive a copy of the [informant information sheet](#).

- *If possible* stay with them whilst they read this through and answer any questions that they have. If they would like to go ahead, arrange a suitable time.
- *If they don't have time to read the information then*, leave it with them, and make sure they know where to find us! – point out Suzie's photo on the front of the easy read information, her contact details on the back, and good locations and ID e.g. t-shirts.

Conducting interviews

General information

- With **INAS** athletes, interviews can be conducted face-to-face or over Skype. **You do not need to conduct the WASI-II with INAS athletes.**
- With **all other athletes**, the interview needs to be conducted at least partially face-to-face, in order to conduct the WASI-II. However, the interview can be broken up, so that for example the WASI-II is done face-to-face, and the ICF-based interview is done face-to-face and/or over Skype at another time.
- Ideally, the WASI-II should be completed in one sitting
- The ICF-based questionnaire can be completed over multiple sittings.
- **Only those familiar with, and with experience in conducting, the WASI-II will complete this part of the interview.**
- **When talking about the WASI-II, to reduce anxiety do not use the name or call it a test.** Instead, talk about it as a short assessment, or a couple of tasks, that will give you an idea about things they're great at, and not so good at.

Introduction

- Make sure that both the athlete and informant have read through their information sheets
 - Ask them if they need any help. You, or the informant, can read the athlete through the information sheet, if necessary
- Ask them if they have any questions (familiarise yourself with the FAQ section in **Appendix A**)
 - If there's any questions you're unsure about, please find or call Suzie! In the unlikely event that there's a question you can't answer, please arrange another time to meet.

Consent form

- Introduce the consent form as something that you're asking everyone who takes part to complete. This is to make sure that they are happy to take part in the research.
- Complete their **ID code**. This is a number starting at 1 (for the first person you interview) followed by **your** initials.
- As with the information sheet, if necessary you or the informant can read the statements out to the athlete
- The athlete can then sign or tick the boxes, if they agree
- The athlete then needs to write their name, sign and date at the bottom of the form. Please add your own name and signature.

Throughout the interview

- Emphasise at the beginning, and at regular intervals throughout (e.g. at the start of each new section of the ICF-based questionnaire) that the athlete can take a break, or stop. Reiterate that they can complete the interview at another time, either in person (if possible) or via Skype (Suzie doesn't have access to Facetime, but if you do, and you're happy to complete the interview at another time, please feel free to offer this as an option!).

Starting the interview

If applicable, ask the athlete if they would like to start with the WASI-II or the physical health interview. If you are short of time, you might like to suggest starting with the WASI-II.

Completing the WASI-II

- It is OK for informants to be present during this part of the interview, but ask them not to contribute.
- Complete this as normal, using the given text.
- You only need to complete the 2-subset form, i.e. the Vocabulary and Matrix Reasoning tests.
- You will therefore need to adapt the introductory text so that it does not include information on the Similarities and Block Design tests.

Completing the ICF-based interview

General tips

- Text in *black italics* are instructions for you to read out loud for the athlete
- You only need to say the information included in blue and in brackets [] if further information is requested
- Record answers on the Excel spreadsheet, after entering their ID code and information on the event. Information on coding answers (i.e. on severity of the problem) is at the top of the spreadsheet. If you are able to use this that would be very helpful, but otherwise please feel free to write out all their answers, giving as much information as possible.
- Sometimes people interrupt! If they do, see if there's anything else in the question that might be important to clarify. For example, if they answer 'No' after 'Do you have problems with consciousness?', follow this up with 'Any problems with blackouts or fainting?'
- The ICF-based questionnaire covers problems that have been an issue over the last four weeks. Therefore, if someone is experiencing a current problem (for example very itchy eyes from hayfever; restricted range of movement from an injury) then this should be recorded
- Sometimes people mention that they have a physical health problem, such as asthma, but then later say that they have no problems with breathing. In these cases, provide a prompt, such as, "Earlier on you were telling me that you have asthma. Does that sometimes give you problems with breathing?". If it is well controlled with medication then it can be marked as 0 (no problem).

- The informant is there to help contribute to the interview. For example, they can help with communication, particularly to help the athlete communicate if they do not understand something. There may sometimes be disagreements between the informant and the athlete regarding whether something is a problem, or how much of a problem it is. Use this as an opportunity to open up the conversation and try to come to an agreement.
- Feel free to keep the interviews light! Let athletes talk around things if they'd like to, or acknowledge that some questions might seem strange (for example, if appropriate, that you're asking a fit elite athlete about their exercise tolerance!)
- Also feel free to use gestures, for example miming touching something hot (Q29a).
- When printing out the questionnaire to use, please keep the font size and layout. These have been developed with service user consultation.



Appendix A

ICF-based interview with athletes with learning disabilities: Researcher protocol - FAQ

What is the title of the study?

What can athletes with intellectual disability (ID) tell us about taxonomic frameworks applied to ID?

What does that mean in plain English?!

- We're looking at how learning disabilities are categorised and thought about.
- We think that physical health is an important factor that should be considered with all people with learning disabilities.
- We are talking with athletes about this to develop a questionnaire about physical health in people with learning disabilities.
- We think that if the questionnaire is sensitive enough to pick up difficulties with athletes then it will be a good questionnaire to use with all people with learning disabilities.

What are the aims?

- a. Can the ICF-based questionnaire discriminate between three groups of athletes with ID plus different levels of physical/sensory disabilities, i.e.:

1. elite athletes with INAS (hypothesised to be unrepresentative of athletes with ID due to a low level of additional physical disabilities)
 2. sub-elite athletes (hypothesised to have a mixed number of additional physical disabilities)
 3. athletes with Down's Syndrome (DS).
- b. Given the proposal discussed above that groups 2 and 3 will experience additional difficulties, the ICF-based tool will highlight a significant number of additional difficulties in these two groups, even when IQ is controlled for.

ICF-based questionnaire illustrate a pattern of physical health and additional characteristics (e.g. ASD) within each of these three groups of athletes?

- d. Can the ICF-based questionnaire be validated against pre-existing (i.e. INAS) data on physical health and additional characteristics (e.g. ASD)?
- e. As IQ scores decrease, the overall ICF-based questionnaire score (i.e. the total number of additional disability) will increase.

Will this work have an impact on the Paralympics?

- This project is being conducted with Canterbury Christ Church University and INAS. We have no link with the Paralympics
- At the moment, athletes with ID can compete with INAS and at the Paralympics. However, if they also have a physical health problem then they rarely qualify to compete, as it is an unfair playing field.
- This research will go towards helping INAS to create an additional competing class for athletes with ID and a physical health problem.
- We hope that this work will be a step in the process for creating an additional competing class at the Paralympics, but this is a long process

What if the athlete has difficulties with communication?

- We would like to encourage athletes with a broad range of abilities to take part in this research.
- This is to make sure that the questionnaire we have developed works for everybody.
- This is part of the reason that we are making sure that the athlete is interviewed with someone that knows them well, so that they can help the athlete answer the question, if necessary.
- The only reason we would say an athlete should not take part in the research is if they are not able to give their consent to take part.

Appendix M: Interim report to athletes



Physical health in athletes with intellectual disabilities: What we found out



Thank you for taking part in my research!



This sheet will tell you **what we found out**.



The research was with **INAS**, the International Sports Federation for Persons with Intellectual Disability, and **Canterbury Christ Church University**.



We want to get more people with intellectual disabilities to take part in **sport**.

We think that **physical health** is important. We think it might be stopping some people with intellectual disabilities taking part in sports.



I talked to 11 people who worked with athletes with intellectual disabilities.



They helped me make a **questionnaire about physical health** for people with intellectual disabilities.



I talked to **77 athletes!** We did the questionnaire together.



We found that different athletes had different problems with their **physical health**.



We found that athletes with Down syndrome had **more problems** with their physical health than athletes with INAS.

We think there should be another competing class for athletes with Down Syndrome.



But we need to do **more research** for other athletes with learning disabilities and physical health problems.

What will happen next?



We hope to let other people know what we find. We will do this by writing a paper which could be **printed** or be put on the **internet**.



This paper would talk about **everyone together**. No one reading the paper will be able to tell that you took part, unless you tell them.



Good luck for your next sporting event!

Suzie Lemmey
Trainee Clinical Psychologist

Supervised by Jan Burns, Professor of
Clinical Psychology

Appendix N: Statement of ethics

A statement of ethics has not been included. This is because data collection will continue for the purposes of publication. The ethics committee will be informed when this has been done.

Appendix O: Submission guidelines for the International Review of Sport and Exercise

Psychology

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