REASONABLE ADJUSTMENTS TO PROVIDE EQUITABLE AND INCLUSIVE ASSESSMENT, SCREENING AND TREATMENT OF OSTEOPOROSIS FOR ADULTS WITH INTELLECTUAL DISABILITIES: A FEASIBILITY STUDY

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INTRODUCTION

Research on osteoporosis and fracture risk in people with intellectual disabilities (IDs) is limited, yet it is a recognised concern that people with IDs are a high risk population for developing osteopenia or osteoporosis, due to a higher prevalence of risk factors, which lower bone mass density (BMD), which are more relevant to this population (Srikanth et al, 2011). The World Health Organization (2004) defines osteopenia as BMD between 1 and 2.5 standard deviations (SDs) below the typical young adult (30 years old) mean (T-score -1 to 2.5), and osteoporosis as BMD more than 2.5 SDs below the young adult mean (T-score <2.5). The consequence of osteoporosis is that it leads to bone fragility and a marked increase in susceptibility to bone fracture (World Health Organization, 2004). The main contributory factors for osteoporosis and fracture risk in the population of IDs include being prescribed anti-epileptic drugs, immobility, diagnosis of Down's syndrome, and having a history of falls or previous fractures (Srikanth et al, 2011; Tyler et al, 2000). People with IDs – particularly people with severe or profound IDs – can be up to fifty times more likely to experience epilepsy (Lhatoo, 2001), compared to the general population, and up to fourteen times more likely to have musculoskeletal impairments, or related conditions (e.g. cerebral palsy), which can cause partial mobility or immobility (Emerson et al, 2012). Down's syndrome is a common genetic cause of IDs, and people with Down's syndrome are more likely to experience health problems which lower bone density, such as early menopause for women (Emerson et al, 2012). In addition, people with IDs experience similarly high rates of falls as older adults without IDs in the general population, but throughout their lives at any age, and they are more likely to experience fractures (Finlayson, 2018).

Vitamin D deficiency is common in the general population and likely to be more prevalent in vulnerable groups who may be outdoors less, including people with IDs. Vitamin D deficiency may be associated with adverse effects on bone health including osteomalacia and increased fracture risk. Vitamin D supplementation is often recommended for use in vulnerable groups, including those taking anti-epileptic drugs and those with reduced sunlight exposure (NICE , 2017; NICE, 2016; Public Health England, 2016).

Diagnosis of osteoporosis through assessment and screening therefore, is important to define the requirement for treatment interventions to prevent fractures.

Assessment and screening of fracture risk

Dual-Energy X Ray Absorptiometry (DXA) is considered the gold standard for diagnosis of osteoporosis (World Health Organization, 2004; SIGN, 2015). The procedure for measuring BMD with a DXA scan however, can present issues for some people with IDs, as it involves the person lying still on the scanner throughout the procedure. Some people with IDs may not be considered for a DXA scan if they are immobile (unable to transfer on to the table), unlikely to be able to tolerate lying still during the scan (e.g. people with attention deficits or hyperactivity), or if they have spinal deformities, such as scoliosis (curvature of the spine) or contractures (Angelopoulou et al, 1999).

In the United Kingdom (UK), the two main tools to predict risk of osteoporotic fracture are the Fracture Risk Assessment Tool (FRAX) (Kanis et al, 2008) and QFracture (Hippisley-Cox, 2009; Hippisley-Cox, 2012). Both of these assessment tools ask a series of questions, which are based on the main risk factors identified for osteoporosis in the general population (listed in *table 3*), which are then used to compute an algorithmic score to indicate the person's risk of experiencing osteoporotic fracture and major osteoporotic fracture over a 10-year period. These tools are used by clinicians to identify patients at high risk of fracture, who may benefit from interventions to reduce their risk. However they are unlikely to be suitable for use with people with IDs, because they do not consider the additional factors which are more likely to lower bone density in this population; namely Down's syndrome, immobility, and epilepsy (FRAX does not include epilepsy but QFracture does). It is likely that fracture probability scores in adults with IDs will vary markedly between these two tools, as they do in the general population.

Previous research

Seven previous studies on osteoporosis in people with IDs who live in the community have been published (Coppola et al, 2012; Srikanth et al, 2011). One study found BMD to be 2 standard deviations lower in adults with IDs (n = 94) compared to age-matched controls in the general population (Center et al, 1998). Three studies found that between 55% (59 of 107 persons), 58% (173 of 298 persons), and 82% (18 of 22 persons) of adults with IDs screened had osteopenia/osteoporosis (Srikanth et al, 2011; Zylstra et al, 2008; Tyler et al, 2000). Two studies conducted with 67 adults (Baptista et al, 2005) and 22 children (Angelopoulou et al, 1999) with Down's syndrome found their BMD to be lower compared to age-matched controls in the general population. The most recent study on children and young people with

IDs and cerebral palsy with or without epilepsy (n = 113) found that those with epilepsy had a significantly lower BMD compared to those without epilepsy (Coppola et al, 2012).

Six of these previous studies did use DXA screening to measure BMD, but three scanned alternative parts of the body (upper and lower limbs, or the calcaneus) (Srikanth et al, 2011; Baptista et al, 2008; Tyler et al, 2000). One study resorted to administering sedatives or muscle relaxants to children and young people with IDs prior to conducting their scans (Coppola et al, 2012).

Reasonable adjustments

Despite being a high risk population for osteoporosis and fractures, people with IDs are not being offered osteoporosis assessment and screening as part of their routine health care (Srikanth et al, 2011). People with IDs can experience barriers to accessing appropriate and optimum health care; this includes their bone health care due to the issues already described in the previous section on assessment and screening. These barriers include lack of knowledge or awareness amongst clinicians of the specific health needs of people with IDs, lack of access for wheelchair users, and lack of accessible information in easy read/pictures/symbols format for people with communication difficulties (Emerson et al, 2012).

In the UK, the Equality Act 2010 (Government UK, 2015) is addressing inequalities in access to health care experienced by people with disabilities, as it is now a statutory requirement that health care providers make ‘reasonable adjustments’ to ensure people with disabilities have

equity of access to their services. 'Reasonable adjustments' refer to removing physical barriers to access and, importantly, making whatever alterations are necessary to ensure services work equally well for people with disabilities as they do for people without disabilities. This has led to the publication of a series of guidelines for making reasonable adjustments to health services for people with IDs; namely eye care (Turner et al, 2013), cancer screening (Turner et al, 2012), and diabetes services (Turner & Emerson, 2013).

No programme of tailored assessment and inclusive screening for osteoporosis and fracture risk has been developed for people with IDs in the UK, but is warranted. Making reasonable adjustments to bone health services is an important step towards this.

Research aim

The aim of this feasibility study (Campbell et al, 2000) is to investigate the implementation of reasonable adjustments for 30 adults with IDs, with one or more risk factor for osteoporosis and fracture, to answer the following research questions:

1. What is the feasibility of the identification and implementation of reasonable adjustments to provide more inclusive DXA bone density screening for adults with IDs?

2. Following DXA screening what proportion of adults with IDs are subsequently diagnosed with osteopenia or osteoporosis?

3. How do FRAX and QFracture compare on providing risk estimates and intervention advice in people with IDs?

4. What are the views and experiences of the adults with IDs, their supportive carers (family carers or paid support staff), and the health care professionals working within osteoporosis services, on the identification and implementation of reasonable adjustments to provide more inclusive DXA screening for people with IDs?

METHODS

Participants and process

Thirty adults with IDs (aged 18 years and over) were recruited on a first come first serve basis (between January 2017 and July 2017) via multidisciplinary community IDs health care teams across National Health Service (NHS) Greater Glasgow and Clyde and NHS Lanarkshire Health Boards in central Scotland, UK. Community IDs health care professionals were asked to distribute accessible project information sheets to clients with one or more risk factors for osteoporosis or fracture. If they were interested in the study, the ID health care professionals contacted the researcher (L. D-A.). Participants and their supportive carers (relatives or support workers) were contacted for a suitable home visit date and time. At the home visit consent was recorded for the person with IDs, or for their nearest relative if they did not have capacity to consent on their own, and a research interview was completed to document; personal characteristics (e.g. age and sex), current prescribed medications and diagnosed health conditions, and any anticipated reasonable adjustment requirements prior to attending a hospital appointment for a DXA scan and blood test. Prior to the hospital appointment, participants were sent an accessible information pack about their hospital visit (this included a DVD of a DXA bone density scan and how to navigate the hospital and parking), and an accessible version of their hospital appointment card. The researcher then liaised with health care professionals working within osteoporosis services (specialist

osteoporosis nurses and DXA machine operators) within the two hospitals where the DXA scans were conducted, to advise on the specific reasonable adjustments identified for each participants with IDs, which would be required during their hospital appointment for a scan. Each participant with IDs attended the hospital appointment for a DXA scan and a blood test. Finally, within four weeks of the hospital appointment, each participant with their supportive carers were visited at home by the same researcher, to complete a second research interview about their views and experiences of their hospital visit, and their reasonable adjustments during the visit.

Ethical approval

This study was ethically approved by the Scottish A Research Ethics Committee, and NHS Greater Glasgow and Clyde and NHS Lanarkshire. The Adults with Incapacity (Scotland) Act 2000 (Scottish Government, 2000) was strictly adhered to at all times. Part 5 of the Act states that any research involving an adult who does not have capacity to give consent must obtain consent from a welfare guardian or (in the absence of an appointed guardian) their nearest relative. Written consent from participants with severe or profound intellectual disabilities in this study, who do not have capacity to give their consent, was obtained from their nearest relative (as none had a welfare guardian appointed). In keeping with the Act, these adults were encouraged to participate in the study (e.g. answer questions on their own) as much as they were able to. This study was registered as a clinical trial on the National Institute for Health Research Central Portfolio Management System (CPMS): reference number GN15OR304.

Measures

Assessment and screening

A questionnaire was developed by the research team, to collect personal and health information about risk factors for osteoporotic fracture (e.g. Down's syndrome diagnosis or being prescribed anti-epileptic drugs) and the general population (e.g. being female or older age) (*table 3*). This information was then checked by each participant's general practitioner (GP) for accuracy, and updated as necessary. In addition, pre-DXA FRAX and QFracture risk of fracture assessments (Hippisley-Cox et al, 2012; Hippisley-Cox et al, 2009; Kanis et al, 2008) were completed with each participant during their first home visit research interview. Across both assessment tools, a 10-year fracture risk threshold of 10% would indicate the need for a DXA (SIGN, 2015).

Fifteen DXA scans were conducted at a hospital in NHS Greater Glasgow and Clyde, and 15 DXA scans were conducted at a hospital in NHS Lanarkshire. DXA scans were performed of the femur and lumbar regions (or of the wrist and forearm). Blood samples were collected at the hospital visits and analysed at the local hospital's Haematology Unit for serum 25-hydoxyvitamin D (25[0H]D) levels (Aspray et al, 2014) and calcium mmol/L (Baird, 2011). Vitamin D thresholds are sufficient >50 nmol/l, inadequate 30 – 50 nmol/l, and deficient < 30 nmol/l (Aspray et al, 2014). Calcium levels within the sufficient adult range are between 2.20 nmol/l and 2.60 nmol/l (Baird, 2011).

Reasonable adjustments

Reasonable adjustments were determined from available literature and guidelines (Turner et al, 2013; Turner & Emerson, 2013; Turner et al, 2012). Four reasonable adjustments were identified and implemented for all participants with IDs, mainly with regards to providing accessible information (*table 4*). Accessible information refers to providing information in easy read, pictures and/or symbols formats for people with IDs who may have communication difficulties.

The questionnaire used during the first home visit research interview asked each participant with IDs (with their supportive carer) whether they would require any of a further eight reasonable adjustments listed for them (*table 4*). An alternative DXA scan of the wrist and forearm was offered as one of these reasonable adjustments for those who could not tolerate the femur and lumbar scan. Participants were also asked if there were any other reasonable adjustments they were likely to require prior to or during their hospital appointment.

Views and experiences of the reasonable adjustments

Participants with IDs with their supportive carers completed a second home visit research interview with the researcher, to learn about their views and experiences of their hospital visit and the reasonable adjustments which had been identified and implemented for them. Questionnaire items were comprised of 5-point Likert scales using smiley faces, to illustrate very happy to very unhappy, with space provided for the researcher to document verbatim comments.

Osteoporosis health professionals at both hospitals also completed a postal questionnaire about their views and experiences of the reasonable adjustments which had been identified and implemented for these individuals with IDs within their services. This questionnaire comprised 5-point Likert scales to rate their views on i) the importance, and ii) the ease of implementation of reasonable adjustments within their services; and their agreement with a series of statements (e.g. '*All hospitals should have a reasonable adjustments policy'*).

Copies of all project materials developed by the research team for the purpose of this study are available by contacting the correspondence author.

Analysis

The statistical computer package *IBM SPSS version 23* was used to generate descriptive and frequency statistics. All of the participants with IDs were recruited into the study because they had one or more risk factor for osteoporosis. There was not enough variation within the sample therefore, to conduct inferential or multivariate analyses to investigate significance of associated factors.

Participants' responses to open-ended questions during interviews were collected verbatim and confirmed with the participants and their carers' during the interviews. These responses were summarised following content analysis (Lavrakas, 2008).

RESULTS

Sample characteristics

Seventeen (57%) participants were male, average age was 44 years, and the majority of participants have severe or profound IDs (16, 54%). Nineteen (63%) have epilepsy and 8 (27%) have Down's syndrome (*Table 1*).

**********Insert *table 1* about here**********

Assessment, screening and treatment

Of the 30 participants with IDs, 29 (97%) were able to complete a femur and lumbar spine DXA scan, once reasonable adjustments had been implemented. One participant, a wheelchair user with profound IDs, was able to complete a wrist and forearm DXA scan as a reasonable adjustment, but the quality of the DXA image was still compromised. Hence, DXA T-score results for 29 adults with IDs are presented in *table 2*. Of these, osteopenia and osteoporosis was detected in 11 (38%) and 12 (41%) respectively.

**********Insert *table 2* about here**********

Five participants chose not to give a blood sample. Vitamin D and calcium blood test results are also presented in *table 2* for 25 (83%) participants. Seven (28%) of these participants were already being prescribed vitamin D supplements by their GPs. Serum 25-hydroxyvitamin D (25[OH]D) levels were generally low. Treatment is recommended when serum 25-hydroxyvitmin D levels are less than 30 nmol/L (Aspray et al, 2014). Twelve

(48%) participants had levels below this. Treatment is also recommended when serum 25-hydroxyvitmin D levels are in the range of 30 – 50 nmol/L when the person has a high fracture risk, has reduced sunlight exposure or is taking anti-epileptic drugs (SIGN, 2015). Five (20%) participants had levels within this range. The majority of the 25 participants had sufficient calcium blood levels.

Of the 23 (79%) adults with IDs who were identified as having osteopenia/osteoporosis following DXA screening, the consultant on the research team (SG or RM) recommended drug/supplement treatment for 22 (73%); this included the 7 adults with IDs already being prescribed vitamin D supplements (whereby the treatment advice was to continue with the supplements for 4 persons, and change medication or increase the dose for 3 persons). One older adult with IDs with osteopenia was offered lifestyle and dietary advice.

The most common risk factors for osteoporotic fracture in this sub-sample were: having epilepsy and/or being prescribed anti-epileptic drugs (14 persons); diagnosis of Down's syndrome (7 persons); being immobile (7 persons); history of falls (7 persons); and previous fractures (7 persons) (*table 3*).

FRAX collects information about previous fracture and supports risk calculation from a minimum age of 40 years. Twelve (40%) of the adults with IDs in this study were below the age of 40 years, so 40 instead of their actual age was inserted to complete their FRAX assessment. FRAX calculated the mean (standard deviation; range) % fracture risk within the next 10 years as being 4.7 (2.5; 1.8 – 12.0) % for this sample. FRAX scores (freely available

at http://www.sheffield.ac.uk/FRAX) identified that BMD measurement would likely be required for 12 (52%) participants.

QFracture collects information about previous fracture, epilepsy or anti-epileptic drugs, and history of falls. QFracture supports fracture risk calculation from a minimum of 30 years, so once again, for 5 (17%) adults with IDs the minimum age instead of their actual age was inserted to complete their assessment. The main application of QFracture is to estimate fracture risk prior to carrying out a DXA scan. Within this sample of adults with IDs, the mean (SD; range) % fracture risk within the next 10 years was 3.7 (3.7; 0.5 – 16.3) %.

Alternatively, QFracture (freely available at http://www.Qfracture.org) utilises an intervention threshold, whereby women identified as having more than 11.6% risk of fracture, and men identified as having more than 2.6% risk of fracture, will require treatment intervention. Of the 30 adults with IDs in this study, their QFracture scores determined that 7 (32%) would require treatment intervention; all seven of whom did receive treatment intervention following DXA screening.

Reasonable adjustments

Table 4 provides a summary and some quotes (views and experiences) about the reasonable adjustments identified, implemented and evaluated with the adults with IDs and their supportive carers. This includes six additional reasonable adjustments which were anticipated by some of the adults with IDs and their supportive carers themselves; particularly having their carer with them at all times during their appointment (18 persons), and having an

appointment time which fitted around their daily, mainly morning, routines (11 persons). Importantly, the majority of reasonable adjustments presented in *table 4* (14 out of 18 which were not mandatory for all participants) were individual (personalised) to the person with intellectual disabilities.

**********Insert *table 4* about here**********

Seven osteoporosis health care professionals (4 nurse specialists and 3 radiographers) provided questionnaire feedback on the implementation of these reasonable adjustments within their services. Six agreed or strongly agreed that their participation in this study has increased their awareness of the specific bone health needs of people with IDs (one felt they were already aware due to working with people with dementia); but only three agreed or strongly agreed their participation had increased their confidence in working with people with IDs (four stated they were already confident about this). All seven agreed or strongly agreed that they feel comfortable communicating with people with IDs during their appointments.

All seven osteoporosis health care professionals felt each of the reasonable adjustments identified in this study were important and very important, and easy or very easy to implement within their services; except for an alternative DXA scan of the wrist and forearm, whereby two were less sure of how important or easy it was to offer as a reasonable adjustment. More generally, seven agreed or strongly agreed that all hospitals should have a reasonable adjustments policy, and six agreed or strongly agreed that all hospitals should have a learning disabilities champion (Shaw et al, 2012).

DISCUSSION

This is the first published study which has identified, implemented, and evaluated reasonable adjustments with people with IDs, their carers', and health care professionals in a UK health care setting. Making reasonable adjustments are key to promoting equitable and optimum health care to avoid compounding health inequalities for people with IDs (Tuffrey-Wijne & Hollins, 2014; Tuffrey-Wijne et al, 2014). Following a *Confidential Inquiry* into the premature deaths of 244 people with IDs (90, 37% were avoidable), Heslop et al (2014) made the following recommendations: (1) People with IDs should have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may be delivered differently to achieve the same outcome; and (2) Reasonable adjustments required by, and provided to individuals, should be audited annually and examples of best practice to be shared across agencies and organisations.

This study has determined that people across all levels of IDs can complete DXA screening of their femur and lumbar regions – which is the gold standard and routine practise with the general population – once reasonable adjustments have been identified and implemented. Twenty-nine (97%) successfully completed a DXA scan of their femur and lumbar regions, despite over half having severe or profound IDs (16 participants, 54%) and problem behaviours (16 participants, 54%).

Eighteen reasonable adjustments were implemented, including six which were identified by the adults with IDs and their supportive carers themselves. They particularly valued having

their carer with them during the DXA procedure (18 persons), and having an appointment time which fits around their daily, especially morning, routine (11 persons). The latter is a new finding not reported elsewhere in the literature, and it was found to be more important to the participants overall than being offered an appointment during a quiet time (6 persons), or being offered a pre-visit to the hospital before their appointment (zero persons). No participants were unhappy or very unhappy with any of the reasonable adjustments implemented for them and they were all evaluated as being very important or important, and very easy or easy to implement, by the osteoporosis health professionals who took part in the study (except for an alternative DXA scan, which fewer felt was important or easy to implement).

Making reasonable adjustments is an important step towards more inclusive assessment and screening for osteoporosis for people with IDs, as they are at greater risk of osteoporosis and fracture. It is currently not known how many adults with intellectual disabilities are included or excluded from DXA BMD assessment in the UK, or how many have received DXA BMD assessments unsuccessfully, but the results from this study do indicate that osteopenia/osteoporosis is being under detected in individuals with intellectual disabilities who may be at risk who have not previously received a DXA assessment. Within the 29 adults with IDs, osteopenia was detected in 11 (38%) and osteoporosis was detected in 12 (41%); 23 (79%) in total. These are similar percentages to a previous smaller UK study (n = 18) (Srikanth et al, 2011). BMD measurements at sites other than spine and/or femur do not predict whether patients will benefit from anti-osteoporosis drug therapy, so although one reasonable adjustment implemented was a scan of the wrist and forearm it was not helpful. Ultrasound is an alternative method of BMD screening, but it is not widely available in UK

hospitals, and there is no advice on using results as a means of targeting therapy (SIGN, 2015), so was not considered for this study.

A recent UK study found that adults with IDs *and* mental health problems (n = 155) were twice as likely to have vitamin D deficiency, compared to the general population (n = 192) (Frighi et al, 2014). This current study found that of 25 adults with IDs (not just adults with IDs and mental health problems) identified as being at risk of osteopenia or osteoporosis, 12 (48%) were found to have low vitamin D levels, and a further 5 (20%) were found to have very low vitamin D levels. Vitamin D deficiency and other factors which can increase risk of developing osteoporosis and fragility fractures e.g. being prescribed anti-psychotic drugs which increase prolactin, which reduces sex hormones, should be taken into consideration when assessing individuals with intellectual disabilities. With regards to the latter, anti-psychotic treatment is common in people with intellectual disabilities who are more likely to experience mental health problems and behaviours which challenge (Sheehan, 2017).

FRAX and QFracture are sex and age adjusted. Unlike the general population, men with IDs are just as likely as women with IDs to develop osteoporosis, and at a younger age. FRAX and QFracture have not been evaluated in a population of adults with IDs and do not consider some risk factors for fracture that are prevalent in this population. For example, falls and fall injuries are more common in people with IDs (Finlayson et al, 2018). Although QFracture does ask about falls, it is currently not possible to include this to the FRAX algorithm, so clinicians have been reminded that repeated falls will increase fracture risk (Masud et al, 2011). Treatment decisions can differ depending on the fracture calculation tool used when coupled with certain intervention thresholds. QFracture may be more promising in this

respect, and it is recommended in local guidance (SIGN, 2015), but clinicians will need to bear in mind the increased fracture risk in men and women with IDs with additional risk factors.

Strengths and limitations

The main strength of this study was the close-working with adults with IDs, their carers', and osteoporosis health care professionals, to complete DXA BMD scans of the femur and lumbar regions with personalised reasonable adjustments. Although 29 (97%) participants received a usable DXA scan, 5 (17%) chose not to give a blood sample, due to an apprehension or fear of needles. Perhaps further adjustments could have been anticipated to overcome this, such as the use of an anaesthetic cream or spray on the skin to numb the skin when the needle is inserted (Public Health England, 2017; Abuelkheir et al, 2014).

Of the 25 adults who did give a blood sample, 17 (57%) were found to have low or very low vitamin D levels, but no control group was used for comparison. It is known that the general population in Scotland (due to e.g. latitude and climate) has lower vitamin D levels than populations in other countries, including other countries in the UK (Hypponen & Power, 2007).

The main limitation of this study was the convenience sample and the recruitment method, which meant there would have been some selection bias in who was offered the study information. However, this was appropriate for study design, and a larger proportion of adults

with severe or profound IDs were able to participate, than would have been the case for a representative sample of adults with IDs in the UK (Emerson et al, 2012).

Whilst each of the eighteen reasonable adjustments identified and implemented in this study were positively evaluated by people with IDs, their carers', and the osteoporosis health care professionals, no cost analysis was conducted. Future studies should consider this, as it will be important to know which of these adjustments are reasonable in terms of cost to services as well (e.g. longer appointment times).

CONCLUSION

People across all levels of IDs, and with associated conditions (e.g. autism), can successfully undergo DXA BMD screening, once reasonable adjustments have been implemented. Eighteen reasonable adjustments were identified by the research team and participants themselves, although not all were deemed important to those with IDs or osteoporosis professionals. Providing people with IDs with appointment times which fit around their daily (morning) routines, and the carer being present during the appointment, were found to be particularly important to people with IDs and their carers'. Other adjustments appreciated were longer appointment times and the option of a hoist or a car parking space for disabled persons at the hospital. These reasonable adjustments can be personalised, and should be implemented to ensure equitable access for all. Adults with IDs across all levels of IDs can complete a fracture risk assessment including DXA BMD screening, once reasonable adjustments have been implemented. Reasonable adjustments identified by adults with IDs and their carers' are mostly easy to implement and rated as important by osteoporosis

professionals. Implementing these reasonable adjustments would contribute to reducing inequalities in health care for adults with IDs. There is a need to increase the uptake of DXA BMD screening for individuals with intellectual disabilities who are at risk of developing osteoporosis and fragility fractures, once reasonable adjustments have been implemented, otherwise, as this study shows, a high proportion of those with osteopenia/osteoporosis will remain undetected. High levels of vitamin D deficiency but not low blood calcium levels were seen and these tests should be routinely considered. Current fracture risk tools are not appropriate for this population. Future research and practice should focus on the interaction between risk factors, fracture risk and BMD to reduce the morbidity of adults with IDs.

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Table 1: Whole sample characteristics and health conditions

	N = 30 (100%)
Age	Mean = 44 years (range 20 – 66 years, SD 13.33)
Sex:	
Male	17 (57%)
Female	13 (43%)
Ethnicity:	
Caucasian	28 (94%)
Chinese	1 (3%)
Pakistani	1 (3%)
Lives with…	
Family	13 (44%)
Supported living	10 (33%)
Congregate care	6 (20%)
Alone, independently	1 (3%)
Cause of intellectual disabilities:	
Unknown	19 (63%)
Down's syndrome	8 (27%)
Meningitis	2 (7%)
Tuberous sclerosis	1 (3%)
Level of intellectual disabilities:	
Mild	7 (23%)

Moderate	7 (23%)
Severe	7 (23%)
Profound	9 (31%)
Has cerebral palsy:	
Yes	9 (30%)
No	21 (70%0
Has epilepsy:	
Yes	19 (63%)
No	11 (37%)
Has autism:	
Yes	3 (10%)
No	27 (90%)
Has a mental health problem:	
Yes	11 (37%)
No	19 (63%)
Has problem behaviour/s:	
Yes	16 (53%)
No	14 (47%)
Number of prescribed drugs	Mean = 6 (range 0 – 17, SD 4.44)
Number of known medical conditions	Mean = 3 (range 0 – 9, SD 2,38)

Table 2: DXA scan and blood test results

	Mean	**Range**	**Standard Deviation**
DXA results N = 29			
Lumbar 2 - 4 BMD*	1.061	0.704 – 1.599	0.237
Lumbar 2 - 4 T-score	-1.360	-4.500 – 3.000	1.987
Lumbar 2 – 4 Z-score	-0.825	-3.900 – 3.500	1.816
Neck of femur BMD*	0.821	0.545 – 1.265	0.188
Neck of femur T-score	-1.676	-4.000 – 1.500	1.502
Neck of femur Z-score	-1.167	-3.600 – 1.700	1.289
Total hip BMD*	0.852	0.582 – 1.339	0.187
Total hip T-score	-1.600	-3.900 – 1.900	1.457
Total hip Z-score	-1.200	-3.400 – 2.000	1.227
Blood test results N = 25			
Serum 25-hydroxyvitaminD (25[OH]D) nmol/l	50.160	13.000 – 144.000	39.554
Calcium (adjusted) nmol/l	2.317	2.140 – 2.520	0.091

* BMD = bone mass density

Table 3: Proportions of sample with presence of risk factors identified for osteoporotic fracture risk in adults with IDs and the general population

	Whole sample **N = 30 (100%)**	**Subsample with presence of osteopenia/osteoporosis** **N = 23 (100%)**	**Subsample with presence of osteoporosis only** **N=12 (100%)**
Factors relevant to people with intellectual disabilities (IDs)			
Level of IDs	Mild 7 (23%) Moderate 7 (23%) Severe 7 (23%) Profound 9 (31%)	Mild 5 (22%) Moderate 5 (22%) Severe 6 (44%) Profound 7 (30%)	Mild 3 (25%) Moderate 1 (8%) Severe 2 (17%) Profound 6 (50%)
Down's syndrome	8 (27%)	7 (30%)	2 (17%)
Immobility	8 (27%)	7 (30%)	7 (58%)
Factors included in FRAX and QFracture			
Age	Mean 44 years Range 20 – 66 SD 13.33	Mean 45 years Range 20 -66 SD 14.3	Mean 44 years Range 20 – 66 SD 16.9
Sex	Male 17 (57%) Female 13 (43%)	Male 14 (61%) Female 9 (39%)	Male 8 (67%) Female 4 (33%)
BMI	Mean 26 Range 18 – 40 SD 5.72	Mean 25 Range 16 – 36 SD 5.8	Mean 22 Range 16 -29 SD 5.4
Current smoker	0 (0%)	0 (0%)	0 (0%)
Alcohol status	1 (3%)	1 (4%)	1 (8%)

Rheumatoid arthritis	5 (17%)	5 (22%)	2 (17%)
Parent had a hip fracture	2 (7%)	0 (0%)	0 (0%)
Previous fracture	9 (30%)	7 (30%)	4 (33%)
Factors included in FRAX only			
Glucocorticoids	0 (0%)	0 (0%)	0 (0%)
Secondary osteoporosis	8 (27%)	0 (0%)	0 (0%)
Factors included in QFracture only			
Ethnicity	Caucasian 28 (94%) Chinese 1 (3%) Pakistani 1 (3%)	Caucasian 22 (96%) Chinese 1 (4%) Pakistani 0 (0%)	Caucasian 11 (92%) Chinese 1 (8%) Pakistani 0 (0%)
Epilepsy or antiepileptic drugs	19 (63%)	14 (61%)	9 (75%)
Lives in congregate care	6 (20%)	4 (17%)	2 (17%)
History of falls	9 (30%)	7 (30%)	2 (17%)
Diabetes	0 (0%)	0 (0%)	0 (0%)
Dementia	3 (10%)	3 (13%)	1 (8%)
Cancer	0 (0%)	0 (0%)	0 (0%)
Asthma or chronic obstructive pulmonary disease	3 (10%)	2 (8%)	2 (17%)
Heart attack, angina, stroke or transient ischemic attack	0 (0%)	0 (0%)	0 (0%)
Chronic liver disease	0 (0%)	0 (0%)	0 (0%)
Chronic kidney disease	1 (3%)	0 (0%)	0 (0%)
Parkinson's disease	0 (0%)	0 (0%)	0 (0%)
Malabsorption e.g. (Crohn's disease)	1 (3%)	1 (4%)	0 (0%)
Endocrine problems (e.g. thyrotoxicosis)	4 (13%)	4 (17%)	1 (8%)
Antidepressants	7 (23%)	5 (22%)	1 (8%)
Steroid tablets	0 (0%)	0 (0%)	0 (0%)
Oestrogen only hormone replacement therapy	0 (0%)	0 (0%)	0 (0%)
Lack of sexual characteristics	8 (27%)	6 (26%)	2 (17%)
Menopause	8 (27%)	6 (26%)	2 (17%)

Table 4: Reasonable adjustments implemented and their evaluation by the participants with IDs with their supportive carers

Reasonable adjustment	**Anticipated prior to hospital appointment N = 30**	**Participant evaluation rating N=29***	**Participants' comments**
Mandatory (implemented for all participants with IDs in the study)			
Accessible information pack about the hospital and the hospital appointment.	Mandatory.	Very happy or happy 22 (76%), and neutral (neither happy nor unhappy) 7 (24%).	*'All the information was useful, not too long. It indicated the toilets and made me feel very comfortable'* (42 year old woman with moderate IDs).
Accessible hospital appointment card.	Mandatory.	Very happy or happy 23 (79%), and neutral 6 (21%).	*'Brilliant. It suggested what to wear and that was excellent. The clock and calendar made [person with IDs they care for] understand better the information. Pictures are also important to explain what is going to happen'* (Carer of 21 year old man with moderate IDs).
Accessible DVD demonstrating a DXA scan during a hospital appointment.	Mandatory	Very happy or happy 24 (83%), and neutral 6 (17%).	*'Watching the DVD helped me not to be scared'* (40 year old man with mild IDs). *'I watched it and I knew what I could experience, made me less anxious'* (30 year old woman with mild IDs).
Telephone reminder from the researcher about their hospital appointment (two days before the appointment).	Mandatory	Very happy or happy 29 (100%).	*'It was already in my diary but it was a nice wee thing to check if anything had changed in our family plans. We felt cared for. For most of her appointments we do not have that. It was unusual'* (Carer of 20 year old woman with profound IDs).

			'I am okay to answer the phone. [My support workers] have a communication book where they write down appointments but I can't look into it' (36 year old man with mild IDs).
Offered as a reasonable adjustment to individuals with IDs in the study:			
A pre-appointment visit to the hospital to become familiar with the hospital and/or the room where the DXA scan will be conducted.	0 (0%; although 22, 73% did say they had visited a hospital before for a scan, x-ray or operation).	Overall rating of hospital facilities: Very happy or happy 23 (79%), and neutral 6 (21%).	*'I used them. I was happy with the toilets'* (47 year old man with profound IDs). *'I know where the toilet is. I don't want to get lost'* (58 year old man with severe IDs). '*Directions [to the hospital] and disabled parking and cafeteria are all relevant parts, and all of this is to let you know things in advance. You knew before going what was going to happen'* (Carer of 47 year old man with profound IDs). *'We knew where to go in the hospital and where to have a cup of tea afterwards'* (Carer of 36 year old man with mild IDs). *'Parking information is very important. If you get lost inside the hospital you ask someone, but parking is more confusing, even in hospitals, even if you have not been there before'* (Carer of 47 year old man with profound IDs). *'It was nice to get soup after and the*
Access to a toilet before, during or after their appointment.	Yes 16 (53%; of which 7, 23% would require specific access to a toilet for disabled persons). No 14 (47%).		
A disabled car parking space at the hospital, for those travelling to the hospital in a private household car.	Yes 17 (57%). No 13 (43%).		
A snack or refreshment before, during or after their appointment.	Yes 14 (47%). No 16 (53%).		

			toilets were good' (58 year old woman with mild IDs).
A longer appointment time (e.g. double appointment).	Yes 17 (57%). No 13 (43%).	Overall rating of appointment time of day and duration: Very happy or happy 28 (96%), and neutral 1 (4%).	*'This is very important, so that it is not rushed. The nurses were very kind and everything we needed [a hoist] was there so we didn't have to wait for it'* (Carer of 65 year old woman with severe IDs). *'It was alright. Not rushed. I know the scan does not take long but it is more about the time [person with IDs they care for] can take getting undressed'* (Carer of 52 year old man with severe IDs). *'Twenty minutes would have been fine because [person with IDs they care for] cooperated on the day, but he is unpredictable so it is useful to have extra time'* (Carer of 58 year old man with IDs). *'He was seen very quickly, so that helped [person with IDs they care for]. He did not get agitated. He was calm'* (Carer of 52 year old man with profound IDs).
An appointment during a quiet time (e.g. first or last appointment of the day).	Yes 6 (21%). No 24 (79%).		
The use of a hoist or sling to transfer on to the DXA machine (for 8 wheelchair users in the study).	Yes 7 (23%; all of whom were wheelchair users). No 23 (77%).	Overall rating of DXA scan procedure: Very happy or happy 28 (96%), and neutral 1 (4%).	*'In general, hospitals are not prepared when we arrive, and it seems they do not expect to have her in a wheelchair…There is more need of understanding how (the person with IDs they care for) is…It was good to have*
An alternative DXA scan of the wrist and	Yes 1 (3%; who was a		

forearm (for those who could not tolerate a DXA scan of their femur and lumbar regions e.g. unable to lie still).	wheelchair user). No 29 (97%).		*someone [researcher] that could take care of everything, made it easier…it gave more support to the family. People with IDs feel like nobody cares of them and that they are not listened to, so this [study] was beneficial from that point of view'* (Carer of 45 year old woman with profound IDs). *'I was hoping that with the wrist and forearm DXA scan we could have done it when she was sitting in her wheelchair…These [DXA machines] should be more accessible, allowing to have a DXA scan without stretching the arm on the bed'* (Carer of 45 year old woman with profound IDs).
Further reasonable adjustments anticipated by the participants with IDs and their supportive carers, and implemented:			
Having the person with IDs' carer with them during the procedure.	Requested by 18 (63%).	Overall rating of inclusion in osteoporosis assessment and screening: Very happy or happy 28 (96%), and neutral 1 (4%).	*'It suited us perfectly, just after lunchtime. [Person with IDs they care for] had his breakfast before and we had time to be ready. It suits our needs to prepare'* (Carer of 44 year old man with profound IDs. *'That was a good time for us. We had enough time to dress and feed [person with IDs they care for] and give ourselves time to drive there comfortably'* (Carer of 20 year old woman with profound IDs). *In the end [person with IDs they care for] seemed to have had enough. I was very*
An appointment time which fits around, thus does not disrupt, the person with IDs' daily, particularly morning, routine.	Requested by 11 (37%).		
Playing the person with IDs' favourite music or music in general during the procedure to relax and/or distract them.	Requested by 4 (13%).		
The person with IDs having a light snack (e.g. piece of chocolate) or drink just before or immediately following the procedure, to incorporate something he/she likes.	Requested by 2 (7%).		
Speaking directly (or talking things through) to	Requested by 1 (3%).		

the person with IDs during the appointment, to explain during the procedure what is happening and what is happening next.			*proud of her though. The first part was very good but she got anxious when the machine was going towards her face. Next time I need to remember to bring the video of the actor she likes to distract her'* (Carer of 42 year old woman with moderate IDs). *'I did not like to be moved around on the scan. I prefer they tell me what to do'* (36 year old man with moderate IDs).
Providing a quiet environment as much as possible with e.g. no sudden or loud noises.	Requested by 1 (3%).		

*One participant with IDs could not complete a second home visit research visit evaluation due to ill health.