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Improving the physical health of adults with intellectual disabilities who live in residential settings

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Improving the physical health of adults with intellectual disabilities

who live in residential settings.

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for the degree of Doctor of Philosophy

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Declarations

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any other degree.

Signed………………………………………………………. (candidate)

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Statement 1.

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Summary

The purpose of this thesis was to address two broad research questions. The first was to explore the associations between physical and mental health in adults with ID who live in residential settings. Given the considerable numbers of adults with intellectual disabilities who live within residential settings, it is somewhat surprising how little systematic research attention has been given to this area. The second aim of this thesis, was, in collaboration with a local service provider, to design and implement interventions to improve the health of adults with ID who live in residential settings.

To address these two broad research aims, it was first necessary to develop an appropriate method to measure the physical activity levels of adults with ID. Given the wide range of ability levels of adults with ID in these settings, it was decided to design a measure that proxy respondents, for example, support staff, could complete. Chapter 2 describes the process of validating this measure and the results showed that this measure had very good criterion validity for measuring physical activity levels over a seven-day period when compared to data gathered from an accelerometer during the same period.

Chapter 3 begins the work of describing the physical health, mental health and challenging behaviours of adults with ID who live in residential settings, using descriptive data. Chapter 3 also describes the associations between physical health, mental health and challenging behaviour using correlational and regression methods. The data revealed relatively poor physical health in terms of the number of residents who were overweight, obese or morbidly obese, who did not participate in adequate levels of physical activity, and in terms of the numbers of adults with ID who displayed the signs and symptoms of physical ill-health. Physical health variables accounted for some of the additional variance in mental health problems and problem behaviours.

Chapter 4 describes the results of a systematic review and meta-analysis summarising the evidence for multi-component weight-loss interventions for adults with ID. Despite these types of interventions being carried out for several decades (e.g. Fisher, 1986) and these types of interventions being the treatment of choice for adults who are overweight or obese (e.g. NICE, 2006) only eight studies met inclusion criteria for this review. All of the eight studies reported that adults with ID lost weight between pre- and post-intervention. However, when all of the studies were combined, the pre- to post-intervention meta-analytic mean difference effect size for changes in BMI and weight were not statistically significant and were also small in terms of clinical meaning.

The final empirical study addressed changes in the physical health of participants as a result of the collaborating service designing and implementing interventions to improve the health of adults with ID within the service. Chapter 5 also looks investigates if improving physical health improves participants' mental health and challenging behaviours over the same 18-month period. The data described in this chapter were the follow-up data of the first survey in Chapter 3. The results showed that between T1 and T2 the majority of participants improved in terms of their physical health. Improvements in some aspects of physical health were also associated with some improvements in mental health and challenging behaviour. However, these associations were once again small in number.

Findings from the three empirical studies were discussed in relation to their theoretical value and their implication in intervention research. Recommendations for further study were also made.

Chapter 1. Introduction: Improving the Physical Health of Adults with Intellectual

Disabilities: An Introduction to Current Research.

The purpose of this thesis is to investigate the physical health of adults with intellectual disabilities and methods to improve their health. Research has consistently shown that adults with intellectual disabilities experience poorer physical health compared to age-matched peers who do not have an intellectual disability. Researchers have also started to demonstrate the associations between poor physical health and higher levels of mental health problems as well as behaviours that challenge. Interventions that aim to improve the physical health of adults with intellectual disabilities are also gaining more research attention. However, little research has focused on putative improvements in mental health and behaviours that challenge as a result of improving physical health. It is important to fully explore these issues. If research can show that improving physical health can lead to additional improvements in mental health and behaviours that challenge, these data could potentially be valuable in helping to improve the quality of life for all adults with intellectual disabilities who live in residential services.

To set the context for the research presented in this thesis, it is necessary to present a brief overview of recent physical health research within the ID field. Therefore, I will describe ID, before describing and discussing research in the field of ID. In particular, the focus will be on physical health research in the field of ID, with an emphasis on improving the physical health of adults with ID who live in residential settings.

An introduction to Intellectual Disability

Intellectual disability (ID) is characterised by: "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18." (American

Association on Mental Retardation, 2002, p.1). These deficits must manifest during childhood and before the age of 18 and are therefore distinct to those caused by acquired head injuries in adults. Intellectual disabilities affect adaptive behaviours and skills (used for activities of daily living, communication, social interaction, work and leisure activities), as well as general intelligence (as measured by IQ; Baroff & Olley, 1999).

ID is classified on the basis of an individual's IQ. To be classed as having ID, an individual's IQ must fall approximately two standard deviations below the population mean, therefore an IQ of below 70. It is possible to further classify an individual's level of ID: people with mild ID have an IQ of between 50-55 and 70, people with moderate ID are said to have an IQ of between 35-40 and 50-55, people with severe ID have an IQ of between 20-25 and 35-40, and people with profound ID have an IQ below 20-25 (Baroff & Olley, 1999).

Currently in the UK, approximately 1.5 million people are estimated to have an ID, and 46,298 of these live in residential homes, while 4,863 people live in residential homes with nursing care (Care Quality Commission, 2009).

Physical health research within the field of intellectual disability

Since deinstitutionalisation, people with ID are now living in the community and are more frequent consumers of mainstream health care (Beange, 2002). Whereas institutions once met their health needs, adults with ID are now responsible for their own health, with support if required, and need to access the same health services as the population without ID. Deinstitutionalisation has made the health inequalities between people with and without ID more obvious (Beange, 2002).

Adults with ID are at significant risk for physical health problems and morbidity compared to those without ID. Adults with ID have both general health needs, which are comparable to those without ID, and special health needs, which are more common in people with ID (Kerr, 2004). Older people with ID are more likely to suffer from chronic diseases such as heart disease and stroke (Draheim, 2006; Merriman, Haw, Kirk & Stubbs, 2005), whereas younger adults with ID are more likely to experience physical health problems, such as epilepsy (Morgan, Baxter & Kerr, 2003), sensory impairments and dermatological and neurological conditions (Cooper, 1997) compared to people who do not have an ID. Adults with a mild ID are also more likely to be obese and to smoke tobacco compared to their peers (Draheim, 2006). Numerous studies have documented a high prevalence of health problems in adults with ID, yet they generally use health services less and are less likely to benefit from health promotion materials and initiatives (Cooper, 1997; Jones, McLafferty, Walley, Toland & Melson, 2008).

The risk factors for physical ill health within the field of intellectual disability

Research has demonstrated factors that consistently correlate and predict physical and mental illness in adults with ID. Many illnesses are associated with syndrome-specific conditions. For example, Down syndrome is associated with congenital heart, gastrointestinal, eye and ear defects as well as certain types of cancer including leukaemia (Evenhuis, Henderson, Beange, Lennox & Chicoine, 2000). During adulthood, people with Down syndrome experience a higher incidence of specific endocrine (especially hypothyroidism), cardiac, oral, infectious, dermatological and musculoskeletal problems (Roizen & Patterson, 2003). As older adults, people with Down syndrome are more likely to exhibit age-related changes,

such as loss of vision and hearing, epilepsy and dementia at an earlier age (Evenhuis *et al.,* 2000).

Adults with milder ID, who live in the community, may engage in unhealthy behaviours that do not promote a healthy lifestyle. Research has consistently shown that individuals with ID have low levels of physical fitness and cardiovascular endurance (Lotan, Yalon-Chamovitz & Weiss, 2009); have low physical activity levels (Durstine, Painter, Franklin, Morgan, Pitetti & Roberts, 2000**;** Emerson, 2005; Stanish, Temple & Frey, 2000); lead sedentary lifestyles (for example: Lotan et al., 2009); and are more likely to be obese (for example: Lynnes, Nichols & Temple, 2009) compared to individuals who do not have ID. Reduced physical and cardiovascular fitness is likely to result from inadequate opportunity for adults with ID to engage in physical activity and exercise, rather than as a function of a biological condition (Stein, 1977). It is also likely that individuals with ID have difficulties understanding the effects that their behaviours are having on their health, while not appreciating that highly-demanding, health-promoting behaviours, such as healthy eating and exercise, have long-term benefits (Lancioni, Singh, O'Reilly, Oliva, Campodonico & Groeneweg, 2004). All of these behaviours may contribute to ill health, such as cardiovascular disease, hypertension and diabetes, which have been noted in adults with ID living in different settings.

Being female, of an older age, having a mild-moderate ID, living in the community, having low levels of physical activity, using psychotropic medication, having friends and social opportunities, and having Prader-Willi, Cohen or Bardet-Biedl syndromes are all known to correlate with higher levels of obesity (Melville, Hamilton, Hanker, Miller, & Boyle, 2007). A poor diet is commonplace in adults with ID. Research has shown that only 19-22% of people with ID eat the recommended 5

portions of fruit and vegetables daily (Robertson *et al.,* 2000). A poor diet has been

shown to be associated with bowel cancer and cardiovascular disease (Robertson *et*

al.).

Living arrangements are also predictive of health problems. For example,

adults who lived, or continue to live, in large institutions are at a risk for past or

present exposure to a number of infectious diseases, such as hepatitis B, helicobacter

pylori and tuberculosis (Beange, 2002).

Socioeconomic status (SES) is an important determinant of health for all

individuals, with lower SES correlating with increased prevalence of disease,

disability, lung cancer, coronary heart disease, accidents and suicide in the general

population (Graham, 2005). Many adults, and children, with ID are disproportionately

represented within lower SES groups, and they are also known to have higher health

needs. The 1958 birth cohort study showed that children with mild-to-moderate ID

were more likely to have emotional difficulties, sensory impairments and to be in

contact with psychiatric services, while during adulthood, mild ID was associated

with long-term illness, disability, and depressed mood, particularly in women

(Maughan, Collishaw & Pickles, 1999).

Improving the physical health of adults with intellectual disabilities

Internationally, policies exist to ensure that in principle, all adults with ID

have access to adequate health services. Each of the four countries of the UK has their

own policies on how to ensure access to healthcare for adults with ID: England-

Valuing People Now: A new three year strategy for people with learning disabilities

(Department of Health, 2009); Scotland - *The same as you: a review of services for*

*people with learning disability (*Scottish Executive, 2000); Northern Ireland - *Equal*

lives: Review of policy and services for people with a learning disability in Northern

Ireland (Department of Health and Social Security, 2005); and Wales- *Fulfilling the*

promises: Report of the Learning Disability Advisory Group (Learning Disability

Advisory Group, 2001). Although each of these policies address health inequalities

and disparities for adults with ID in different ways, they focus on issues such as all

adults with ID having access to general healthcare (with support when required),

medical staff having adequate training on the needs of people with ID and that health

promotion materials are provided in an accessible format. As a result of having

higher physical health needs and accessing health care services less than the general

population, screening for physical health problems has also become a priority for

healthcare services. Annual health checks (including screening) were welcomed by

adults with ID, carers and health professionals when initially introduced, however

uptake could be higher – in Wales uptake was reported at 42% for 2008/9 (Perry,

Kerr, Felce, Bartley & Tomlinson, 2010).

Mental health and challenging behaviour research within the field of intellectual

disability

            Research suggests that adults with ID suffer from the same mental health

problems as the general population and it has also been reported that their prevalence

is higher in people with an ID (for example: Dosen & Day, 2001; Cooper, *et al.*,

2007; Smiley, *et al.*, 2007). Thus, there are likely significant mental health

inequalities for adults with ID as well as physical health inequalities. The Welsh

Health Survey (Welsh Office, 1996) found that adults with ID had a higher rate of

psychiatric illness (32.2%) compared to the general population (11.2%). Research has

also shown that the prevalence of global mental illness across men and women, of all

ages and levels of ID ranged from 16% to 54% (Holden & Gitlesen, 2009). In a large-scale population-based study, Cooper, Smiley, Morrison, Williamson and Allan (2007), found that the presence of any psychiatric disorder varied according to the diagnostic criteria used, from 40.9% (clinical diagnosis) to 15.7% (DSM-IV-TR criteria). Risk factors for mental ill-health in adults with ID follow a bio-psycho-social continuum, with genetic abnormalities, abnormal brain structures, stigmatization, lack of adaptive behaviours, lack of social contact and poor education being important contributors (Azam *et al.*, 2010).

Challenging behaviour, or behaviours that challenge, are terms used to describe a variety of "culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities" (Emerson, 1995, pp. 4-5). Challenging behaviours may include self-injurious, aggressive, socially inappropriate, destructive, uncooperative, or stereotyped/ repetitive behaviours. Research suggests that between 75% and 90% of adults with ID will display at least one behaviour that challenges (Deb & Hunter, 1991; Eyman & Borthwick, 1980; Rojahn *et al.*, 2001). However, the prevalence of more severe challenging behaviour ranges from 6-7% (Emerson, 1995; Joyce *et al.*, 2001). Behaviours which challenge can have a detrimental effect on quality of life of people with ID and are likely to impact on individuals in the long-term due to the reported persistence of these behaviours (Emerson *et al.*, 2001; Murphy *et al.*, 2005).

Associations between psychiatric symptoms and challenging behaviours in adults with ID have been identified (Holden & Gitlesen, 2003). It has also been suggested that the signs and symptoms of mental illness are strongly correlated with

maladaptive behaviors (Moss, Emerson, Kiernan, Turner, Hatton & Alborz 2000).

Challenging behaviour may be caused or may be intensified by a coexisting mental

health problem (Emerson, Moss & Kiernan, 1999). Moss (2000) suggested that an

increase in the severity of behaviours which challenge are associated with an increase

in the prevalence of mental health symptoms, with the most marked association being

seen with depression.

Associations between physical ill health, mental health problems and behaviours that

challenge within the field of intellectual disability.

As outlined above, adults with ID experience physical and mental health

disparities compared to adults without ID. The relationships between physical and

mental illness in adults without ID are well established (for example Moussavi,

Chatterji, Verdes, Tandon, Patel & Utsun, 2007). Recently, research has started to

focus on these associations in adults with ID.

Research shows that the incidence of mental illness in adults with ID is

correlated with moderate to severe ID, Down syndrome, abuse/adversity in adulthood,

having a paid carer, urinary incontinence and impaired mobility (Smiley *et al*, 2007).

Incidence of problem behaviour can be predicted by severe ID, abuse/adversity in

adulthood, having a paid carer, being a former long-stay hospital resident, having a

life-event in the previous 12 months, urinary incontinence and impaired mobility

(Smiley *et al*., 2007). Certain illnesses have also been shown to be predictive of

behaviour problems. For example, Davidson, Janicki, Ladrigan, Houser, Henderson

and Cain (2003) showed that passivity is associated with auditory and visual

impairments, gastrointestinal, genitourinary, neurological and cardiovascular

disorders and neoplastic disease, while aggressive behaviour is correlated with

auditory and visual impairments, gastrointestinal, genitourinary and neurological

disorders. Research has also shown that pain may result in lack of responsiveness,

non-compliance, withdrawal or aggressive behaviour (Cooper, Smiley, Jackson,

Finlayson, Allan, Mantry & Morrison, 2009). Mental illness has been reported as one

of the causes of functional decline in older adults with ID (Davidson *et al.,* 2003).

Certain chronic physical health problems are associated with higher rates of mental

health problems, For example, in the general population, research suggests that up to

50% of patients with epilepsy will develop mental health problems, with the most

common being depression, anxiety and psychotic disturbances (Marsh & Rao, 2002),

and as many people with ID have epilepsy, it is likely that epilepsy may be an

important risk factor for mental ill-health in this population.

There has been little research on the associations between mental and physical

health problems in adults with ID. The prevalence of mental and physical health

problems are much higher in adults with ID (Kerr, 2004; Sutherland, Couch &

Iacono, 2002; Welsh Office, 1996). It is important to robustly establish if associations

exist between them, because these associations raise the possibility of improving

psychological well-being, by improving physical health, and vice versa, improving

physical health by improving mental ill-health.

Structure of the thesis

The remainder of the thesis comprises five chapters, four research chapters

and a discussion chapter. Each of the empirical chapters has been, or will be,

submitted for publication and thus is written as a stand-alone piece of work. In the

thesis, the intention was to address two broad research questions. The first was an

exploration of the associations between physical and mental health in adults with ID.

Secondly, working with a local service provider organisation, intervention to improve physical health in adults with ID was a core interest. In exploring the latter research domain, considerable practical difficulties were experienced and early in the research journey, it became clear that some methodological development would be useful as a contribution to the research field.

Physical activity is an important determinant of physical health for all adults. Accurate methods for measuring physical activity levels for research purposes are required. At the time of writing, no proxy respondent physical activity questionnaires exist for use with adults with ID. Thus Chapter 2 focuses on the development of a proxy-respondent physical activity questionnaire, to assess whether adults with ID take part in adequate levels of physical activity, as defined by the World Health Organisation (WHO; 2005). Carers (family members as well as paid support workers), from both residential as well as community settings, recorded the time adults with ID engaged in physical activity, of different intensities, for a period of seven days. The physical activity questionnaire was validated through the use of tri-axial accelerometers, which adults with ID wore for the same seven-day period. Results suggested that the proxy-respondent physical activity questionnaire is a valid measure for assessing health-promoting levels of physical activity, for research purposes, in adults with ID.

Chapter 3 describes the results of a correlational study of physical and mental health of adults with ID who reside within a residential service. The study was designed to identify the physical and mental health needs of this population, as well as measuring the frequency and severity of behaviours that challenge. In addition to reporting descriptive data, the associations between physical health, mental health problems and behaviours that challenge are also reported using correlational and

regression methods. The data revealed relatively poor physical health in terms of body mass index (BMI), the signs and symptoms of physical ill health and low levels of physical activity with many participants not engaging in adequate levels of health-promoting physical activity. Many participants experienced mental health problems as well as behaviour that challenges. Analyses of the relationships between physical health, mental health problems and behaviour that challenges, revealed few associations between physical health, mental health and challenging behaviour in adults with ID. Physical health variables accounted for significant variance for the presence of some mental health problems and challenging behaviours.

As a result of finding significant numbers of participants being overweight or obese within the study reported in Chapter 3, a systematic review and meta-analysis was conducted to summarise the evidence for multi-component weight-loss interventions for adults with ID. The collaborating service was interested in understanding evidence for interventions they might incorporate into their clinical service at a later date. Chapter 4 describes the results of this systematic review and meta-analysis.

Chapter 5 describes the changes in the physical health of participants over an 18-month period – as a follow-up from the study reported in Chapter 3. In the time between the first survey (Chapter 3) and follow-up study, the collaborating service had instigated a number of changes in relation to physical health. In particular, there had been a focus on improving physical activity levels, body mass index (BMI), and improved relationships with the local GPs. From the literature reviewed to inform the study in Chapter 3, it was clear that there were very few studies exploring the relationships between improved physical health and mental health and challenging

behaviours in adults with ID. The implications of these changes are also explored in

Chapter 5.

Chapter 6 forms a discussion chapter that brings together the findings from the

empirical research and makes recommendations for further research within the

domain of improving the physical health of adults with ID who live in residential

settings. Implications for applied uses for the research are also discussed. The thesis

ends with a call for more work in this area to be carried out.

Chapter 2: Validation of a proxy respondent version of the International Physical

Activity Questionnaire for use with adults with intellectual disabilities.

Abstract

Background   Adults with intellectual disabilities (ID) engage in lower levels of physical activity compared to those without ID, despite the well-known physical health and mental health benefits of engaging in regular physical activity. It is vital that researchers are able to accurately record physical activity levels in this population. Adults with ID may find it difficult to record their physical activity levels using traditional physical activity questionnaires. The main aim of this present paper is to report initial data on the validity of a proxy-respondent version of the International Physical Activity Questionnaire (IPAQ-pr) for use with adults with all levels of ID.

Methods   16 adults with ID and their carers (paid support or family members) took part in this study. The adults with ID were asked to wear an accelerometer for a period of seven days. During the same seven day period their carers were asked to complete the IPAQ-pr.

Results   The IPAQ-pr has good criterion validity between data extracted from the IPAQ-pr when compared to the accelerometer data. The IPAQ-pr has very good criterion validity when measuring the association between two categorical variables (meeting or not meeting WHO recommended physical activity levels; $\kappa_c = 0.818$, p= .001, 95% CI 0.479, 1.157). The IPAQ-pr has excellent criterion validity when measuring the association between time (hours) spent engaged in physical activity over a seven-day period ($r_S= 0.958$, p<.001).

Conclusions   Initial data suggest that the IPAQ-pr is a valid method for measuring physical activity in adults with ID. Further research is needed to validate the IPAQ-pr with more adults with ID, especially with people with more severe levels of disability. The implications for practice are also discussed.

Key words: adults, physical activity, intellectual disability, monitoring, validation

Individuals with intellectual disabilities (ID) are reported as having lower

levels of physical fitness and cardiovascular endurance (Lotan, Yalon-Chamovitz &

Weiss, 2009), engaging in lower levels of physical activity (Durstine, *et al.*, 2000**;**

Emerson, 2005; Stanish, Temple & Frey, 2006) and are more likely to lead sedentary

lifestyles (e.g., Lotan et al., 2009) compared to adults without ID. All of these aspects

of limited physical activity may contribute to ill health, such as cardiovascular

disease, hypertension and diabetes, which can result in reduced life expectancies in

adults with ID.

The World Health Organization (WHO; 2000) and the UK National Institute

of Health and Clinical Excellence (NICE; 2006) recommend that all adults should

partake in at least 30 minutes of moderate-intensity physical activity on at least 5 days

of the week. Moderate-intensity physical activity includes activities such as walking,

cycling or swimming, so long as the intensity is high enough to increase individuals'

heart and breathing rates (Pollock *et al.*, 1998). Increased levels of physical activity

are associated with a substantial reduction in the risk for many chronic diseases such

as coronary heart disease, hypertension, hypercholesterolemia, type 2 diabetes,

obesity, osteoporosis and sarcopenia, along with reducing the risks of developing

secondary complications from these chronic conditions (Melzer, Kayser & Pichard,

2004).

Physical activity also has beneficial effects on mental health, including the

reduction in the symptoms of depression and anxiety, as well as increased

psychological well-being (Paluska & Schwenk, 2000). For individuals with ID,

increasing physical activity may have beneficial effects on challenging behaviour

including reduced hostility and anger (Beange, 2002), and self-injurious behaviours

(Neri & Sandman, 1992). For adults with ID who participate in physical activity as

part of a larger group within the community, making new friends and improving their social skills (Mahon, Mactavish & Bockstael, 2000), feeling proud of their achievements (Devine & Lashua, 2002), and increasing self-esteem (Beart, Hawkins, Kroese, Smithson & Tolosa, 2001) have all been reported as positive outcomes. In addition, taking part in physical activity, especially in the community, has been reported as contributing towards changing in the public's perceptions of adults with ID (Beart *et al.*, 2001).

Given the significance of physical activity as a determinant of health and the associated social benefits, methods of measuring physical activity in community and residential settings are vital for the research effort in the ID field. In general samples, people who engage in low levels of physical activity tend to over-report their physical activity levels, whilst those who engage in higher levels of physical activity under-report their physical activity levels due to social-desirability biases (Stanish *et al.*, 2006). Self-reports of physical activity are also heavily reliant on memory and comprehension of information about the intensity of physical activity. Therefore, completing self-reports of levels of physical activity are likely to be a considerable challenge for individuals with ID (Stanish *et al.*, 2006). Accurate and valid measures for recording and measuring physical activity in adults with ID are therefore needed.

The International Physical Activity Questionnaire (IPAQ; Craig, *et al.*, 2003) has been widely used to measure physical activity levels in community samples of people without ID (Hagstromer, Oja & Sjostrom, 2005), and also as a self-report measure in adults with mild to moderate ID (with support from care-givers if required; Melville *et al.*, 2011). The purpose of this paper is to report initial data on the validity of a proxy-respondent version of the IPAQ (IPAQ-pr) for use with adults with all levels of ID.

Method

Participants

Sixteen adults with ID were recruited to take part in the study; five

participants were recruited from service providers in North-West Wales which

provide training and employment opportunities for adults with ID, while the

remainder were recruited from a residential service in North-East Wales. The

residential service provides care for adults with ID who have additional needs, such as

physical health problems, mental health problems, or challenging behaviours. The

sample consisted of 10 males and six females whose ages ranged from 19 years to 58

years (M=32.75 years, SD = 11.13 years), and all 16 were ambulatory. No IQ data

were available for full confirmation of ID diagnosis, but all participants were

administratively defined as being in receipt of services where the presence of an ID

was an eligibility criterion.

Measures

The International Physical Activity Questionnaire (IPAQ; Craig *et al*., 2003)

comprises four questionnaires, with long and short versions for use by either

telephone or self-administration. The short version contains nine items and provides

information about the amount of time that was spent during the last seven days

remaining sedentary, walking, and engaging in moderate and vigorous physical

activity. The long version contains 31 items and provides information about the

amount of time that was spent during the last seven days remaining sedentary,

engaging in household and gardening tasks, engaging in occupational activities,

engaging in self-powered transport and engaging in leisure time physical activity.

Items also include an estimation of the pace of physical activities such as walking and

cycling. The questionnaires can be used to obtain internationally comparable data on

health-related physical activity. Extensive reliability and validity testing was

conducted across 12 countries and results show acceptable psychometric properties

for use with 18-65 year old adults in diverse settings for all four versions (Craig *et al.*,

2003). The IPAQ is also suitable for national population-based prevalence studies of

participation in physical activity.

In the present study, we developed a proxy respondent version (IPAQ-pr;

Appendix A) based on the short version of the IPAQ. Support staff and family

members completed the IPAQ-pr. Support staff and family members were told that

the IPAQ-pr should be completed by the person who had spent the most amount of

time with the adult with ID during that segment of the day (morning, afternoon, or

evening). The IPAQ-pr allows respondents to record the minutes spent by participants

doing physical activity of different intensities, in the morning, afternoon, and evening

each day for seven days. Examples of activities meeting these different intensity

levels were given to respondents, as well as an example of how to complete the

IPAQ-pr. Respondents were also instructed to complete the IPAQ-pr at the end of

each segment of the day (e.g. morning). This is a different method of recording

physical activity to the original IPAQ, which requires people completing the self-

report IPAQ to recall physical activity levels up to a week later.

Apparatus

IPAQ-pr data were validated using information gained from accelerometers.

Accelerometers measure movement in single- or multiple-planes, and as such can

measure the intensity, as well as the frequency of different physical activities (such as

running and cycling) as opposed to just the number of steps walked (Stanish *et al.*,

2006). They provide objective measurement of physical activity levels, and as they do

not require recall of information over a one-week period or subjective assessments of physical activity intensity, they are the ideal equipment for this type of research.

The *activ*PAL3 (PAL Technologies Limited) is a small (5x3.5x0.7cm), lightweight (0.20kg), uni-axial accelerometer, which classifies an individual's free-living activity into time spent sitting, standing and walking. In addition, lower limb movement is used to quantify steps taken and cadence (intensity of physical activity). The *activ*PAL3 accelerometer is worn discretely on the thigh and Palstickies (PAL Technologies Limited), a dual layer hydrogel, are used to securely adhere the accelerometer to the skin. The device can continuously record physical activity levels for up to 10 days as a result of its substantial memory and processing capacity. The accelerometer uses USB connections to interface with a Windows compatible PC and activity patterns are analysed using proprietary algorithms (*activ*PAL Professional Research Edition; PAL Technologies). The software allows data to be presented in either graphical or numerical form, which is summarised in 24-hour segments.

The *acti*PAL3 has been found to be a reliable method for measuring physical activity including treadmill walking, jogging, and self-paced walking, with test-retest reliability and validity reported as very good, and error reported as 1.1% (Dahlgren, Carlsson, Moorhead, Hager-Ross & McDonough, 2010; Ryan, Grant, Tigbe & Granat, 2006).

Procedure

The study was subject to full ethics and governance review by the School of Psychology, Bangor University. Participants and support staff/ family members (proxy responders) were provided with information sheets (Appendices B and C) and shown how to use the accelerometers and how to complete the IPAQ-pr. Functional assessments of capacity were completed with each participant by the first author using

a best practice model based on the Arscott, Dagnan and Kroese (1998) methodology

(Appendix D). If the participants had capacity, researchers asked for their informed

consent to take part in the research using the appropriate consent forms (Appendices

E and F). If the participant did not have capacity to consent to the research they were

excluded from the study. All 16 participants (100%) had the capacity to consent to

take part in the study, and all provided consent.

Each participant received an accelerometer to wear for seven days (from the

time they awoke on the day after they received the accelerometer, to the time they

went to bed on the seventh day). Participants were told to remove the accelerometer

when showering, bathing or swimming. Participants were also provided with

Palstickies to adhere the accelerometer to their leg, along with one copy of the IPAQ-

pr. During the seven days, proxy respondents were asked to complete the IPAQ-pr as

outlined previously. After the seven-day period the IPAQ-pr and accelerometers were

collected.

Data Analysis

The *activ*PAL Professional Research Edition software was used to download

and summarize the physical activity data into 24-hour periods. The first author

calculated the amount of time (minutes) each participant spent walking and engaging

in moderate- and high-intensity physical activity using the data from the IPAQ-pr.

This information was entered into a database, along with the downloaded data from

*activ*PAL accelerometer. Physical activity levels from the IPAQ-pr and *activ*PAL

were coded (into a dichotomous yes/no variable) in terms of whether participants met

the WHO guidelines (2000) for physical activity (>30 minutes of moderate intensity

physical activity on ≥5 days of the week). Physical activity levels from the IPAQ-pr

and *activ*PAL was also coded as *none; Low = <30 minutes a day of walking or*

moderate physical activity on <5 days of the week; Moderate=30 minutes a day of

walking or moderate physical activity on 5 days of the week; High = ≥ 30 minutes a

day of walking or moderate physical activity on 7 days of the week.

Results

Information about participants' gender and age, the respondent who completed

the IPAQ-pr and participants' physical activity levels is described in Table 1.

Physical activity levels are reported in terms of their level (coded as none, low,

medium or high), if they met the WHO guidelines for physical activity during a one-

week period (Yes/No) as well as the total time (in hours) that participants spent

engaged in physical activity over a seven-day period. This information is reported

separately for the IPAQ-pr and accelerometer.

The IPAQ-pr data show that three participants engaged in low levels of

physical activity, six in moderate levels of physical activity and seven in high levels

of physical activity. In comparison, the accelerometer data revealed that four

participants engaged in low levels of physical activity, five in moderate levels of

physical activity and seven in high levels of physical activity. If we use the

accelerometer data as the benchmark, two of the proxy respondents had

underestimated the physical activity levels when recording on the IPAQ-pr, while

only one had overestimated physical activity levels. These disagreements always

resulted in participants being one category above, or below, their actual physical

activity category for the week.

Table 1: Participant Demographics, responder and physical activity levels

Participant Number	Participant Gender	Participant Age	Proxy Responder	Physical Activity Levels (IPAQ-pr)	Physical Activity Levels (*activ*PAL)	Meet WHO Guidelines (IPAQ-pr)	Meet WHO Guidelines (*activ*PAL)	Total Time Active (hours) (IPAQ-pr)	Total Time Active (hours) (*activ*PAL)
1	Male	28	Parent	Low	Low	No	No	1.25	1.43
2	Male	38	Parent	Moderate	Moderate	Yes	Yes	2.75	3.04
3	Male	36	Parent	Low	Low	No	No	2.00	2.36
4	Male	28	Parent	High	High	Yes	Yes	11.50	7.84
5	Male	19	Parent	High	High	Yes	Yes	17.00	16.09
6	Female	21	Staff	High	High	Yes	Yes	14.75	13.47
7	Female	48	Staff	High	High	Yes	Yes	11.25	6.38
8	Female	29	Staff	High	High	Yes	Yes	9.25	9.87
9	Female	33	Staff	Moderate	Moderate	Yes	Yes	3.00	3.16
10	Female	46	Staff	Low	Moderate	No	Yes	2.25	2.73
11	Female	27	Staff	Moderate	Moderate	Yes	Yes	3.00	3.33
12	Male	21	Staff	High	High	Yes	Yes	10.75	11.07
13	Male	32	Staff	Moderate	High	Yes	Yes	3.25	3.84
14	Male	41	Staff	High	Moderate	Yes	Yes	4.00	3.49
15	Male	23	Staff	Moderate	Moderate	Yes	Yes	3.00	3.28
16	Male	58	Staff	Low	Low	No	No	1.50	2.26

Two researchers coded the data from the IPAQ-pr into the relevant physical activity categories. Inter-rater reliability for this process was 100%. Agreement (i.e. the same coding for physical activity levels using both methods) for physical activity levels across the week sampled between IPAQ-pr and accelerometer data was 81.25%. Cohen's Kappa (κ_c) was used to summarise the strength of association between the three categorical variables (low, medium or high levels of physical activity, as captured by the IPAQ-pr and accelerometer separately). This analysis revealed a strong association between data extracted from the IPAQ-pr when compared to the accelerometer ($\kappa_c = 0.71$, $p < .001$, 95% CI 0.41, 1.01).

The IPAQ-pr data show that 13 participants met the WHO guidelines for physical activity, while the accelerometer data revealed that 12 participants met the WHO guidelines for health promoting physical activity levels. Agreement between the two methods for whether individuals met the WHO guidelines for physical activity was 93.75%. Cohen's Kappa (κ_c) was used to summarise the strength of association between the two categorical variables (meeting or not meeting WHO recommended physical activity levels as captured by the IPAQ-pr and accelerometer separately). This analysis revealed a strong association between data extracted from the IPAQ-pr when compared to the accelerometer ($\kappa_c = 0.82$, $p = .001$, 95% CI 0.48, 1.16). Spearman's rho was conducted to assess the strength of the relationship between the time spent (in hours) engaged in physical activity over a seven-day period as measured using the IPAQ-pr and accelerometers. Analyses revealed a very strong association between the IPAQ-pr and accelerometer data ($r_S = .96$, $p < .001$).

Discussion

Agreement on the coding of physical activity over the course of a sampled seven-day period on the IPAQ-pr with accelerometer data was found to be high in the present small study. Thus, there is initial evidence of criterion validity of the IPAQ-pr as a proxy method of gathering data on physical activity in adults with ID.

Previous studies assessing the validity of physical activity measures, which have been completed by proxy respondents and by self-report have reported varying levels of validity when comparing measures such as the IPAQ to accelerometer data (for example: Dinger, Behrens & Han, 2006; Melville *et al.*, 2011). However, these studies validated the IPAQ using the total minutes participants spent engaged in physical activity as opposed to categorizing physical activity in 15-minute segments. Previous studies have also asked proxy responders to recall physical activity levels for the preceding week, while in this study proxy respondents were asked to record physical activity levels at the end of each segment (morning, afternoon, evening) of the day. Perhaps these two reasons may have contributed to the fact that the validity reported in this study is much higher than that previously reported. This study shows that the IPAQ-pr is an acceptable method of measuring physical activity levels in adults with ID, especially when a categorical outcome of physical levels is required.

The main limitation of this study is the small number of participants. However other validation studies of this type have had relatively small numbers of participants (e.g. Momenan, Delshad, Sarbazi, Rezaei-Ghaleh, Ghanbarian & Azizi, 2012). Another limitation is that all 16 participants had the capacity to consent to take part in research and as such are likely to have mild to moderate levels of ID. Future research is needed to validate the IPAQ-pr in adults with more severe and profound levels of ID. Another possible limitation is that the majority of participants were fairly active

as they met the WHO guidelines for weekly physical activity levels. The sample in this study may have been also been biased towards individuals who enjoyed and regularly participated in physical activity. Both of these potential biases may explain why we found higher level of agreement between accelerometer and physical activity questionnaire data compared to previous studies.

Despite the limitations outlined above, this study validated the IPAQ-pr with participants from community and residential settings, and initial results would suggest that the IPAQ-pr could be used in both settings in the future, although further research with more participants is needed. Paid carers, as well as family members, completed the IPAQ-pr. Agreement between the IPAQ-pr and accelerometer data was 100% for family members, while 81.25% for paid support staff for physical activity levels and 93.75% for paid support staff when assessing if participants met WHO guidelines.

This study shows that the IPAQ-pr has very high criterion validity when categorising the weekly physical activity levels of adults with ID, not only in terms of absolute levels but also in terms of participants meeting weekly physical activity level targets, such as those outlined by the WHO. For services, the IPAQ-pr could be widely used to record physical activity levels to ensure that service users are engaging in acceptable levels of health-promoting physical activity every week. Services can also ensure that physical activity is offered as a choice when designing activity programmes, in order to ensure that adults with ID benefit from physical activity in the ways previously described. The IPAQ-pr is also a less obstructive and far cheaper method for researchers wanting to measure global physical activity levels in adults with ID, as opposed to using accelerometers.

Chapter 3. The Associations between Physical Health and Mental Health and Problem Behaviours in Adults with Intellectual Disabilities living in Residential Settings.

A version of this chapter is currently under review with the *Journal of Mental Health Research in Intellectual Disabilities* as: Christian-Jones, C., Rogowski, C. J., Hastings, R.P., Hughes, J. C., Roberts, D., & Lindsay, W. R. The Associations between Physical Health and Mental Health and Problem Behaviours in Adults with Intellectual Disabilities living in Residential Settings.

Abstract

Background   Adults with intellectual disabilities (ID) are at an increased risk for physical health problems, mental health problems and problem behaviour compared to the general population. The main aim of the present study was to explore the associations between physical health and mental health and problem behaviours in adults with ID. A secondary aim of the research was to examine the feasibility of extracting summary information about physical health from a health checklist used in primary care settings.

Methods   Data on physical health (using a health checklist), mental health, problem behaviours, adaptive behaviour (using standard measures) and physical activity (using a proxy diary format) were collected on 95 adults with ID aged 18-65. The adults resided in specialist residential services for individuals with ID and additional complex needs.

Results   Univariate analyses demonstrated few significant associations between physical health and mental health and problem behaviours in adults with ID. Multiple regression analyses revealed that physical health variables accounted for significant additional variance for mental health problems and symptoms of depression. Binary logistic regression revealed that physical health variables accounted for significant additional variance for the presence of self-injurious behaviour (SIB). Smoking was a significant predictor of other mental health problems.

Conclusions   Further research is needed to explore the relationship between physical health, mental health and problem behaviours in adults with ID. Data on physical health from primary care checklists can be extracted for research purposes.

Keywords

adults, physical health, mental health, problem behaviours, intellectual disabilities,

associations.

Adults with ID are at significant increased risk for physical health problems and morbidity compared to the general population. For example, in the Netherlands, children and adults with ID were found to be 2.5 times more likely to have physical health problems compared to those without ID, when comparing General Practitioner (G.P.) records (van Schrojenstein Lantman-de Valk, Metsemakers, Haverman & Crebolder, 2000). Historically, individuals with ID had shorter life expectancies compared to the general population, however this trend is now beginning to change, with people with ID living longer (Haverman, Heller, Lee, Maaskant, Shooshtari & Strydom, 2010).

In addition to physical health disparities, research studies suggest that the prevalence of some mental health problems is higher amongst adults with ID than in the general population (Deb, Thomas & Bright, 2001a, b; Smiley, 2005). In a large-scale population-based study, Cooper, Smiley, Morrison, Williamson and Allan (2007), found that the presence of any psychiatric disorder varied according to the diagnostic criteria used, from 40.9% (clinical diagnosis) to 15.7% (DSM-IV-TR criteria). The prevalence of challenging or problem behaviours is also high in adults with ID, with Deb and colleagues (2001b) reporting that 60.4% of adults with ID display at least one problem behaviour.

Challenging behaviours and mental health problems may be associated in three different ways (Emerson, 2001). Challenging behaviour may be an atypical presentation of the core symptoms of a mental health problem. Secondly, challenging behaviour may result as a consequence of a mental health problem. Finally, a mental health problem may be a motivational basis for challenging behaviours, which were previously established. Overlaps between psychiatric symptoms and challenging behaviours in adults with ID have been identified (Holden & Gitlesen, 2009). It has

also been suggested that the signs and symptoms of mental illness are strongly correlated with maladaptive behaviours (Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000).

Given these established findings of high levels of mental health and behavioural problems, as well as physical health problems, it is important to ask whether physical health, mental health and problem behaviours are related in adults with ID. In the general population literature, physical and mental health is clearly related. For example, chronic physical health problems, such as asthma, angina, diabetes and arthritis are associated with comorbid depression for between 9.3-23.1% of the population (Moussavi, Chatterji, Verdes, Tandon, Patel & Utsun, 2007). Patients with cancer also experience psychological comorbidities, such as depression (22%), anxiety (38%) and post-traumatic distress (12%; Mehnert & Koch, 2008). For adults without ID, the reasons why physical health conditions are associated with mental health problems can include reasons such as illness and their treatments being stressful which may result in mental health problems (Esch, Stefano, Fricchione & Benson, 2002), endocrine and metabolic illness (such as hypothyroidism) affecting the functioning of the neurological system which can result in mental health problems (e.g. Pilhatsch, Marxen, Winter, Smolka & Bauer, 2011), and finally medication (such as steroids) which can affect brain physiology (e.g. Dubovsky, Arvikar, Stern & Axelrod, 2012).

In the ID field, there have been relatively few research studies addressing associations between physical and mental health. Smiley and colleagues (2007) showed that the two year incidence of psychiatric disorder and problem behaviour in adults with ID was correlated with urinary incontinence and impaired mobility. Certain physical health conditions have also been shown to be predictive of behaviour

problems. For example, Davidson, Janicki, Ladrigan, Houser, Henderson and Cain (2003) demonstrated that aggressive behaviour was correlated with auditory and visual impairments, gastrointestinal, genitourinary, and neurological disorders. Physical pain may also result in lack of responsiveness, non-compliance, withdrawn, or aggressive behaviour (Cooper *et al.*, 2009). The reasons for the associations between physical health problems and mental health problems in adults with ID are likely to be similar to those outlined above for adults without ID. For adults with ID, especially more severe ID, challenging behaviour may result from, or be used to communicate, pain or discomfort that are associated with many physical health conditions, such as infections, headache, dental disease, menstruation and gastro-oesophageal reflux disease (GORD; de Winter, Jansen & Evenhuis, 2011).

Other evidence of a relationship between aspects of physical health and mental health or problem behaviours in individuals with ID comes from intervention studies designed to improve a dimension of physical health. For example, Lang, Koegel, Ashbaugh, Regester, Ence and Smith (2010) reviewed studies where physical activity had been used as an intervention for adults and children with ID. A variety of activities were employed (e.g., jogging, weight training, fast walking, running, and cycling). Decreases in stereotypy, aggression, off-task behaviour, and running away were reported following the physical activity interventions. Given that on-task behaviour, academic responding, and appropriate motor behaviour all increased following the physical interventions, fatigue was not likely to be the cause of decreases in challenging behaviour.

The primary aim of the present research was to explore the associations between physical health, mental health and problem behaviours in adults with ID. Physical health information was captured through a health check methodology, and

mental health and problem behaviour data from standard rating scales. To extend previous research, we explored a wide range of physical health indicators and their associations with mental health and problem behaviours.

A secondary aim of the research was to examine the feasibility of extracting summary information about physical health from a health checklist. This is significant because to be able to carry out research addressing the relationship between physical health and mental health in adults with ID, a methodology is needed to capture information about physical health. Following policy developments internationally encouraging regular health checks for individuals with ID, a number of health checklists have been developed (e.g., the "OK Health Check: Matthews, 1997; the Cardiff Health Check: Fraser, Sines & Kerr, 1998). Although these checklists were designed to facilitate the implementation of policy through large-scale public health intervention, a large amount of data is captured. A significant problem, however, is how to extract data from health checklists to derive variables that can be used in research to explore questions other than those of a more descriptive nature.

Method

Service Setting

The service consisted of 15 residential settings (11 on a shared site and 4 in the community), as well as a small specialist ID hospital. The services were all located across North-East Wales and North-West England (UK). The service provides care for adults with ID, who also have additional needs, such as mental health problems, physical health problems, or problem behaviours. All adults with ID supported by the service were eligible for participation in the research. The number of service users per setting ranged from 1 to 17, with a mean of 10.40 individuals per

setting.

Participants

One hundred and two participants were recruited for the study. Seven participants were later removed as they were older adults, aged over sixty five years old, thus leaving a sample of ninety five participants. Overall, the sample consisted of 61 (64.21%) males and 34 (35.79%) females. Their ages ranged from 20 years to 65 years (*M*=41.1, *SD*= 10.7). Aetiology of ID was unknown for 67 participants, while five had Down syndrome recorded in their file and one participant each had the following causes of ID recorded: Rett syndrome, Prader-Willi syndrome, Turner syndrome, Fragile X syndrome, Oral-Facial-Digital syndrome, Ring 13 syndrome, Moebius syndrome, Phenylketonuria, meningitis as a child, and cyanosis at birth. Thirteen participants had a diagnosis of autism recorded on their file alongside their ID. Forty four (46.32%) participants lived in residential settings with seven or more other people, while the other 51 (53.68%) participants lived in residential settings with fewer than seven other people. Fifty eight (61.05%) participants had moderate to severe levels of deficits in adaptive skills (see Measures), with the remainder having mild deficits to average adaptive skill functioning. No IQ data were available for full confirmation of ID diagnosis, but all participants were administratively defined as being in receipt of ID services.

Measures

Six measures were included in the study.

Adaptive Behaviour:

To measure the adaptive skill level of participants, the Adaptive Behavior Assessment System (ABAS-II; Harrison & Oakland, 2003) was used (Appendix G). The ABAS-II is a comprehensive norm-referenced measure that assesses individuals'

adaptive skills and practical independent functioning, as well as their interactions with

others within the community. It is suitable for use from birth to 89 years of age.

Raters score each item using a 4-point Likert-type scale. The choices are: *is not able,*

never or almost never when needed, sometimes when needed, and *always or almost*

always when needed. The Global Adaptive Composite (GAC) and domain scores

have a mean of 100 and a standard deviation of 15. The lowest possible GAC score is

a standard score of 40 for all forms and all age groups. Internal consistency

(Cronbach's Alpha = 0.98-0.99), inter-rater reliability and content validity (0.78-0.98)

are all reported as good (Harrison & Oakland, 2003).

Physical Health:

Specifically developed for adults with ID, the "OK Health Check" (Matthews,

1997) is a checklist to identify and assess physical health needs (Appendix H). The

OK Health Check identifies symptoms relating to all of the bodily systems, including

the gastrointestinal, respiratory, cardiovascular, and neurological systems, as well as

recording dental disease, epilepsy, mental health problems, and sensory impairments.

The OK Health Check also signifies when reviews (e.g., of medication) and screening

(e.g., breast, cervical) are required. The 123 items are answered using *Yes; No; Don't*

Know options and space is provided for additional information at the end of each sub-

section. Inter-rater reliability (between medically trained and non-medically trained

staff; r= 0.92) and construct validity are reported as good (Matthews, 1997) and the

checklist is widely used within community settings for screening purposes (Gates,

2006).

Mental Health:

The Health of the Nation Outcome Scales (HoNOS-LD; Roy, Matthews,

Clifford, Fowler & Martin, 2002) was adapted for use with adults, aged 18-65, with

an ID and provides a method of measuring change in behaviours, functioning, and

mental health problems (Appendix I). The HoNOS items are scored on a scale of 0-4

(*0= no problem; 1= mild problem; 2= moderate problem; 4= severe problem*) with

the highest possible score being 72. The eighteen items have good validity and

reliability and the measure is viewed as acceptable by clinicians (Roy *et al.*, 2002).

The Reiss Screen for Maladaptive Behavior (RSMB; Reiss, 1988) is a

screening instrument for adults with ID (Appendix J). The RSMB is informant based,

and each of the 38 items is scored as: *no problem, problem or major problem.* The

subscales measure symptoms of Aggression, Autism, Psychosis, Paranoia, Depression

(B) Behavioural symptoms, Depression (P) Psychological symptoms, Dependent

Personality, and Avoidant. Each subscale has a threshold score of nine, with scores of

nine or above indicating the presence of a mental health disorder. Good internal

consistency (0.76), inter-rater (0.76), and test-retest reliability (0.69) as well as good

criterion and concurrent validity have been reported (Reiss, 1988).

Behaviour Problems:

To measure behaviour problems we used the Behavior Problems Inventory-

Short Form (BPI-S; Rojahn *et al.,* 2012 a, b; Appendix K). The BPI-S is a 30-item

scale consisting of the three subscales: Self-Injurious (8 items), Stereotypic (12 items)

and Aggressive/Destructive behaviours (10 items). The BPI-S uses two Likert rating

scales per item, a seven-point frequency scale (*0=never; 1=fewer than once a month;*

2=about once a month; 3=about once a week; 4=about once a day; 5=about once

per hour; 6=more than once per hour; 7=once per minute or more), and a three-point

severity scale (*1=mild; 3=moderate; 9=severe*). A weighted score for each item can

be obtained by multiplying the frequency and severity scores. When comparing the

BPI-S to the full BPI-01 (Rojahn, Matson, Lott, Esbenser & Smalls, 2001) the

sensitivity was reported to be high, as were the correlations between the subscales for both the BPI-01 and the BPI-S (Rojahn *et al*., 2012 b).

Cronbach's alpha was calculated for the present sample using the frequency scores for the three behaviour domains. The Self-Injurious Behaviour (SIB) scale had poor internal consistency (Cronbach's alpha =.45), but internal consistency for the aggressive/destructive behaviour scale (Cronbach's alpha =.83) and stereotyped behaviour scale (Cronbach's alpha =.77) was good. It was therefore decided to score SIB as a dichotomy (presence of any SIB vs. absence of SIB). In the analyses reported below, all three dimensions of behaviour problems were scored on the basis of frequency ratings.

Physical Activity:

The International Physical Activity Questionnaire (IPAQ; Craig *et al.*, 2003) comprises four questionnaires, with long and short versions for use by either telephone or self-administration. The questionnaires can be used to obtain internationally comparable data on health-related physical activity. Extensive reliability and validity testing has been conducted across 12 countries and results show acceptable psychometric properties to be used for 18-65 year old adults in diverse settings (Craig *et al.*, 2003). The IPAQ is also suitable for national population-based prevalence studies of participation in physical activity. The process of developing the IPAQ-pr is outlined in Chapter 2 (IPAQ-pr; Appendix A). This measure was used to assess how many minutes a participant spent participating in physical activity, of different intensities, during a seven day period. All participants' physical activity levels were assessed during the same one-week period to avoid confounding factors. The IPAQ-pr has very strong criterion validity between data extracted from the IPAQ-pr when compared to the accelerometer (Chapter 2). The

IPAQ-pr has very good criterion validity when measuring the association between the two categorical variables (meeting or not meeting WHO recommended physical activity levels; $\kappa_c = 0.818$, p= .001, 95% CI 0.479, 1.157). The IPAQ-pr has excellent criterion validity when measuring the association between time (hours) spent engaged in physical activity over a seven-day period ($r_S= 0.958$, p<.001).

Support staff completed the IPAQ-pr. The IPAQ-pr allowed support staff to record the minutes spent by participants doing physical activity of different intensities, in the morning, afternoon, and evening each day for seven days. Examples of what activities met these different intensity levels were given to support staff, as well as an example of how to complete the IPAQ-pr. Support staff were also instructed to complete the IPAQ-pr at the end of each segment of the day (e.g. morning) and that the staff member who had been working closely with the participant during that time period should be the respondent. This is a different method of recording physical activity to the original IPAQ, which requires people completing the IPAQ to recall physical activity levels up to a week later.

Information from the IPAQ-pr was coded as whether participants met the WHO guidelines (2000) for physical activity (>30 minutes of moderate intensity physical activity on ≥5 days of the week). Physical activity levels from the IPAQ-pr were also coded as *none; Low = <30 minutes a day of walking or moderate physical activity on <5 days of the week; Moderate=30 minutes a day of walking or moderate physical activity on 5 days of the week; High = ≥ 30 minutes a day of walking or moderate physical activity on 7 days of the week*.

Procedure

The study was subject to full ethics and governance review by the School of Psychology, Bangor University and approved by the senior management team of the

service provider. Five of the measures were routinely completed for each adult with ID on entering the service and were updated annually as part of the review process. Informed consent was requested for these data to be collected and used for research purposes. The measures were completed by suitably trained staff, such as clinical psychologists and clinical nurse specialists. The only exception being the IPAQ-pr, which was added for the purpose of this study and was completed by support staff.

Study information sheets were provided to potential participants with ID (Appendix L) and to staff who supported those potential participants (Appendix M). Functional assessments of capacity (Appendix N) were completed with each participant by the first author using a best practice model based on the Arscott, Dagnan and Kroese (1998) methodology. If the participants had capacity, researchers asked for their informed consent (Appendix O). If the participant did not have capacity to consent to the research, clinical staff and the first author completed a best interests checklist (Appendix P). A proxy consent form (Appendix Q) was then sent to relatives or services funding the placements (e.g., local government agencies or health boards). If no response was received, a best interests meeting was arranged to discuss the involvement of their person in the research. These meetings included an invitation to family members, placing agencies, and independent mental capacity advocates where necessary (Appendix R).

Fifty four (56.8%) participants were judged as having the capacity to consent and gave their consent to be included in the research, proxy consent (assent) was obtained for 13 (13.7%) participants, and best interests meetings were held for the remainder (28 participants; 29.5%). Ten individuals, who had the capacity to consent, refused to take part in the study. Once consent was obtained, as previously described, data from the clinical files were collected, anonymised, and summarized for research

purposes.

Demographic information, including gender, age (in years), presence of Autism, and living environment (living with >7 other people), was collected from participants' files, by the first author, during the data collection process.

Results

Before addressing the main research question of the study, we explored methods of extracting data from the health check in relation to physical health. A single health index score (i.e, a count of the number of health problems present) would not adequately capture the wide variety of physical health conditions covered by the measure. Therefore, the OK Health Check data were summarised to provide the following information (based on previous research, which suggests that these physical health variables impact on a person's quality of life), and we explored whether each was related to problem behaviours and mental health problems. Further information on how this process of coding was completed is available from the first author.

- *Physical Health Conditions.* Physical health categories were formed as a way of capturing overall physical health excluding all the separately coded variables listed below: 0 = *No physical health problems; 1 = no chronic physical health problems, with any number of non-chronic physical health conditions; 2 = one chronic physical health problem, with any number of non-chronic physical health conditions; 3 = two or more chronic physical health problems, with any number of non-chronic physical health conditions.* Also, the presence of any chronic physical health condition was recorded by developing a separate variable from the overall physical health conditions coding (i.e., a 0—1 coding combing categories 0, 1 vs. 2, 3).

- *Epilepsy* coded as "yes" if participants had a diagnosis of epilepsy

- *Physical Disabilities* coded as "yes" if participants had any physical disabilities

- *Sensory Disabilities* coded as "yes" if participants had any disabilities affecting hearing or vision

- *Polypharmacy* coded as "yes" if participants were taking >7 different medications on a regular basis (Fulton & Allen, 2005)

- *Smoker* coded as "yes" if participants smoked tobacco based products on a daily basis.

- *Body Mass Index (BMI)* was calculated using the formula BMI = weight $(kg)/height^2 (m^2)$. BMI status was coded as underweight (<18.5 kg/m^2), normal (18.6-24.9 kg/m^2), overweight (25-29.9 kg/m^2), obese (30-39.9 kg/m^2) and morbidly obese (>40 kg/m^2) (World Health Organization, 2000). Additionally, participants were coded as overweight/obese/morbidly obese vs. underweight/normal weight (i.e., a dichotomous code for obese vs. not obese).

Table 1: Summary of physical health across the sample.

Physical Health Variable	Number (%)
Physical Health Conditions	
0	13 (13.68%)
0 Chronic, ≥ 0 other	44 (46.32%)
1 Chronic, ≥ 0 other	24 (25.26%)
≥2 Chronic, ≥ 0 other	14 (14.74%)
≥1 Chronic Physical Health Condition	38 (40.00%)
Epilepsy	43 (45.26%)
Physical Disability	18 (18.95%)
Sensory Disability	42 (44.21%)
Polypharmacy	47 (49.47%)
Smoker	20 (21.05%)
Body Mass Index (BMI)	
Underweight (BMI <18.5)	6 (6.32%)
Normal (BMI 19-24.5)	25 (26.32%)
Overweight (BMI 25-29.5)	21 (22.11%)
Obese (BMI 30-39.5)	30 (31.58%)
Morbidly Obese (BMI ≥40)	13 (13.68%)
Overweight, Obese, Morbidly Obese	64 (67.37%)
Physical Activity Levels (IPAQ)	
No Physical Activity	1 (1.05%)
Low level Physical Activity	48 (50.53%)
Moderate level Physical Activity	41 (43.16%)
High level Physical Activity	5 (5.26%)
Meet WHO (2006) Guidelines for Physical Activity	44 (46.32%)

Table 1 summarises information about participants' physical health, physical and sensory disabilities, medication use, smoking status, body mass index (BMI) and physical activity levels. 86.32% of participants had at least one physical health

problem, while 40.00% had at least one chronic physical health condition. Epilepsy,

physical disability and sensory disabilities were common, as was polypharmacy.

Almost one fifth of the sample smoked and 67.37% were overweight, obese, or

morbidly obese, while 53.68% of participants led sedentary lifestyles and as such, did

not meet the recommended weekly levels of physical activity (WHO, 2000).

Table 2: Associations between demographic and physical health variables with mental
health problems and challenging behaviours.

	HoNOS Total Score	BPI: SIB Score Yes/No	BPI: Stereotypical Frequency Total Score	BPI: Aggressive Frequency Total Score	RSMB TOTAL SCORE
Gender	t= 1.06 p=.294	χ^2= 0.33 p=.568	t= 0.06 p=.950	t= -0.04 p=.969	**t= 2.70 p=.011**
Age	r= 0.16 p= .137	**t= 2.09 p=.040**	r= -0.002 p=.988	r= -0.03 p=.634	r= -0.18 p=.109
Living with 7+	t= 1.31 p=.194	χ^2= 0.20 p=.658	t= 0.67 p=.505	t= 1.29 p=.201	t= 1.49 p=.140
ABAS GAC	**r= 0.36 p< .001**	**t= -3.14 p=.002**	**r= -0.34 p=.001**	**r= -0.06 p=.564**	**r= 0.33 p=.003**
Autism	t= -0.86 p=.394	χ^2= 3.24 p=.072	t= -1.58 p=.119	t= -1.09 p=.297	**t= 3.77 p<.001**
Chronic Physical Health Condition (no, yes)	t= -0.92 p=.360	χ^2= 1.05 p=.306	t= 1.72 p=.089	t= 0.50 p=.618	**t= 2.39 p=.019**
Epilepsy	t= -0.26 p=.797	χ^2= 0.23 p=.635	t= -0.62 p=.539	t= 1.02 p=.311	t= 0.48 p=.631
Physical Disability	t= 0.23 p=.819	**χ^2= 5.16 p=.023**	t= 0.91 p=.364	t= 0.40 p=.689	**t= 2.54 p=.014**
Sensory Disability	t= 0.31 p=.761	χ^2= 1.08 p=.299	t= 0.36 p=.723	t= -0.81 p=.421	t= -0.42 p=.678
Overweight/ Obese (no, yes)	t= -0.38 p=.970	χ^2= 1.76 p=.184	t= 0.50 p=.395	t= -1.20 p=.234	**t= 4.43 p<.001**
Physical Activity: WHO Guidelines (no, yes)	t= -0.71 p=.479	**χ^2= -4.05 p=.044**	t= -0.47 p=.639	t= -0.07 p=.943	t= 0.61 p=.542
Smoker (no, yes)	t= 1.40 p=.165	χ^2= 0.16 p=.689	**t= -3.52 p=.001**	t= 0.90 p=.372	t= -0.71 p=.478

Univariate associations between physical health and demographic variables with mental health and problem behaviours are shown in Table 2. The data in Table 2 show that there are some associations between demographic variables, mental health and problem behaviours. These associations were not of primary interest in this research but are included for comparison with previous research.

The data in Table 2 also show that there are some significant associations between physical health variables and mental health and behaviour problems. Chronic physical health conditions were associated with more mental health problems (RSMB). Physical disabilities were associated with self-injurious behaviour (BPI-S) and more mental health problems (RSMB). Smoking was associated with less frequent stereotyped behaviours (BPI-S). Being overweight or obese was associated with more mental health problems (RSMB). Higher levels of physical activity were associated with lower levels of self-injurious behaviour (BPI-S). Epilepsy and sensory disabilities were not significantly associated with mental health problems and problem behaviours and were therefore not analysed further.

Multiple regression analyses were used to assess if physical health variables improved the prediction of mental health problems and/or problem behaviours in adults with ID, over and above the variance accounted for by demographic variables alone. Because each of the demographic variables was associated with at least one mental health or problem behaviour score, all five of these (gender, age, living arrangements, ABAS-II GAC score, and presence of autism) were entered as predictor variables in Step 1 of the regression models, while physical health variables which had shown at least marginally statistically significant associations ($p < .1$) in the univariate analyses, were added as predictor variables for Step 2. These analyses are summarised in Table 3.

Table 3: Regression analysis of mental health and behaviour problems with physical

health predictors.

Model	Predictor Variables	HoNOS Total Score	BPI: SIB[1] Yes/No	BPI: Stereotyped Frequency Total Score	BPI: Aggressive Frequency Total Score	RSMB Total Score
Model 1	Gender	**β = 0.19 p= .060**	Wald = 1.80 p=.180	β = -0.08 p = .462	β = -0.03 p=.781	**β = -0.24 p= .030**
	Age	**β = -0.20 p= .049**	Wald = 0.07 p=.793	β = -0.05 p= .674	β = -0.04 p=.746	β = -0.11 p=.329
	Living with 7+	β = -0.13 p= .205	Wald = 0.28 p= .595	β= -0.08 p = .437	β = -0.10 p=.385	β = -0.09 p=.395
	ABAS GAC	**β = -0.45 p <.001**	**Wald = -5.92 p = .015**	**β = -0.36 p= .002**	β = -0.05 p=.666	β = 0.20 p= .075
	Autism	β = 0.002 p= .983	Wald = 1.56 p= .211	β = 0.08 p= .444	β = 0.15 p=.201	β = -0.11 p=.341
Model 2	Gender	-	Wald = 1.85 p= .174	β = 0.08 p=.465	β = -0.04 p=.727	**β = -0.23 p=.032**
	Age	-	Wald = 0.005 p= .944	β = -0.03 p=.781	β = -0.03 p=.776	β = -0.09 p= .383
	Living with 7+	-	Wald = 2.30 p= .129	β = -0.08 p=.459	β = -0.13 p=.288	β = -0.03 p=.815
	ABAS GAC	-	Wald = -3.64 p= .056	**β = -0.33 p=.007**	β = 0.002 p=.998	β = 0.14 p=.215
	Autism	-	Wald = 2.407 p= .121	β = -0.16 p=.143	β = 0.14 p= .225	β = -0.11 p= .354
	Chronic Physical Health Condition (no, yes)	-	-	β = -0.16 p=.143	-	β = -0.16 p= .158
	Epilepsy	-	-	-	-	-
	Physical Disability	-	Wald = 3.57 p= .059	-	-	β = -0.06 p= .602
	Sensory Disability	-	-	-	-	-
	Overweight/ Obese (no, yes)		-	-	-	β = 0.18 p= .098
	Physical Activity: WHO Guidelines (no, yes)	-	Wald = -2.24 p= .134	-	-	
	Smoker (no, yes)	-	-	β = -0.09 p= .455	β = -0.12 p= .357	-

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[1] Binary Logistic Regression

No physical health variables were included in the regression model for the total score on the HoNOS, however, a significant percentage of the variance in the score was accounted for by demographic variables ($R^2 = .23$, $F(5,87)=5.12$, $p<.001$), with age and the ABAS-II GAC score being significant independent predictors. Adding physical health variables to the regression models for the frequency of stereotyped behaviour (R^2 change = .03, $F(2,81)=1.65$, $p=.198$), the frequency of aggressive behaviour (R^2 change = .01, $F(1,82)=0.86$, $p=.357$) and the total score on the RSMB (R^2 change = .07, $F(3,72)= 2.32$, $p =.082$) failed to account for significant amounts of additional variance in these scores. However, the ABAS-II GAC score was a significant independent predictor for the frequency of stereotyped behaviour ($\beta = -0.33$, $p =.007$).

Binary Logistic regression was used to assess if physical health variables improved the prediction of the presence of SIB. Adding physical health variables to the regression model for the presence of SIB accounted for a significant increased amount of the variance in these scores (Nagelkerke R^2 change = .27, $\chi^2(2)=7.99$, $p=.018$). None of the physical health variables were significant independent predictors in the resulting regression model, however, having a physical disability was of borderline significance as an independent predictor of the presence of self-injurious behaviour (Wald = 3.57, $p=.059$).

Discussion

In general, the results show that participants had fairly good physical health, with only 40.00% participants having more than one chronic physical health problem. Only 13.68% of participants had no physical health problems and this number is comparable to other research of the physical health needs of people with ID (e.g., van

Schrojenstein Lantman-De Valk *et al.*, 2000). However, the participants in this study were far more likely to have multiple chronic physical health conditions when compared to adults without ID (40.% Vs. 21.00%; Vogeli *et al.,* 2007). Levels of polypharmacy were high (49.47%) in this study, reflecting the fact that many of the participants had physical health problems, mental health problems or problem behaviours requiring specialist placement and support. Similar results have been found in other specialist ID services (e.g., Stolker, Heerdink, Leufkens, Clerkx & Nolen, 2001). A large proportion of this study's participants (67.37%) were overweight, obese or morbidly obese. These levels of obesity were higher than those seen in Wales in 2009 in the Welsh Health Survey (57.0%; Welsh Assembly Government, 2010) for the general population and in other UK population-based prevalence studies of adults with ID (48.7%; Bhaumik, Watson, Thorp, Tyrer & McGrother, 2008). In addition, over one half (53.68%) of this study's participants were sedentary and not reaching the recommended physical activity levels per week. The WHO (2000) guidelines recommend 30 minutes of moderate physical activity every week, as these levels have been shown to benefit physical health.

The univariate analyses demonstrated few significant associations between physical health and mental health and problem behaviours in adults with ID. Chronic physical health problems and physical disability were associated with more mental health problems as measured with the RSMB. Previous research has suggested that chronic or long-term illnesses are associated with mental health problems in people with ID and in people without ID (Moussavi *et al.*, 2007; Smiley *et al.*, 2007). Being overweight or obese was associated with more mental health problems, as demonstrated in previous research with adults without ID (e.g. Rivenes, Harvey & Mykletun, 2009), which suggests that people who are obese are more likely to be

depressed and anxious. Smokers were less likely to display frequent stereotyped behaviours. These patterns of results could be explained by the fact that lower frequencies of stereotyped behaviours were also associated with higher adaptive behaviour scores. Higher adaptive behaviour scores also predicted the frequency of stereotyped behaviours during the multiple regression analyses, therefore higher levels of adaptive behaviours may be an important moderator variable in the frequency of stereotyped behaviours. Previous research has also shown that adults with more mild to moderate levels of ID, thus higher levels of adaptive behaviour, are more likely to smoke (Draheim, 2006). Adults with ID who engaged in higher levels of physical activity displayed lower levels of self-injurious behaviour. Interestingly, epilepsy and sensory disabilities had no associations with mental health problems and behaviour problems, contrary to previous research by Davidson and colleagues (2003) and Cooper and colleagues (2007). A recent systematic review has suggested that in general, adults with ID with a diagnosis of epilepsy do not display more problem behaviours or mental health problems compared to people without epilepsy, however specific sub-groups of people (e.g. those who have more frequent, severe, or generalised seizures) may be more likely to display behaviours that challenge (de Winter *et al.*, 2011).

Multiple regression analyses revealed that there are even fewer significant associations between physical health problems and mental health problems and problem behaviours. Physical health variables were only significant in explaining additional variance for the presence of SIB (BPI-S).

The secondary aim of this study was to explore the utility of extracting information about physical health from the "OK Health Check" and from the IPAQ-pr to include in broader health research. At a descriptive level, this exercise was a

success and enabled multiple dimensions of health in the sample to be described. However, the reliability and validity of the data extraction/summary method is not known. Thus, it is possible that the small number of associations between physical health and mental health and problem behaviours in the present study results from poor reliability and/or validity of the methods used. Further validity studies in particular are needed to explore the utility of health check data in wider research.

Another potential limitation of this study is that the sample consisted of adults with ID from a specialist ID service. Participants were generally placed within the service because of additional needs, such as physical health, mental health and behaviour problems. Therefore, ceiling effects on the standardized measures or for physical health status may have attenuated the associations between physical health and mental health or behaviour problems. While it is important to have a good mix of complex problems in the sample, having nothing but complex problems may have reduced the ability to identify actual associations between physical health problems, mental health problems and challenging behaviour. Further research with more representative samples is needed. A final limitation of this study is the relatively small sample size, which may have resulted in lack of statistical power to detect associations. Further larger-scale research is needed. This study, as well as the majority of other studies investigating the associations between physical health problems, mental health and challenging behaviour in adults with ID have been cross-sectional in nature. Future research needs to be of a larger scale, higher quality and longitudinal in nature, in order to establish the patterns of these associations. Given the considerable inequalities in physical and mental health for adults with ID, more research attention of the relationship between physical and mental well-being is needed. As well as more descriptive and stronger epidemiological research, the

potential value of physical health interventions partly as a means to improve mental

health in adults with ID needs to be explored.

Chapter 4. Systematic Review & Meta-Analysis: Multi-Component Interventions for Weight Loss in Adults with Intellectual Disabilities: Systematic Review and Meta-Analysis.

A version of this chapter is currently under review with *American Journal on Intellectual and Developmental Disabilities* as: Christian-Jones, C., Hastings, R. P. & Hughes, J. C. Multi-Component Interventions for Weight Loss in Adults with Intellectual Disabilities: Systematic Review and Meta-Analysis.

Abstract

Background A systematic literature search for studies reporting the effects of multi-component weight loss interventions for adults with intellectual disabilities (ID) identified 8 studies.

Method A fixed effects model meta-analysis was conducted for changes in weight and BMI.

Results The meta-analytic standardized mean difference effect size (Hedges' *g*) between pre- and post- intervention revealed non-significant effects for BMI and weight.

Conclusions The changes observed in individual studies were small, and lower than previously reported in meta-analyses in the non-ID population. Limitations include the small number of studies included and the quality of these studies: only one utilized a control group. Recommendations are made for future research in this field and the implications of this meta-analysis are discussed for theory, policy, and practice.

Obesity is a known risk factor for numerous health problems, such as cancers (Calle, Rodriguez, Walker-Thurmond & Thun, 2003), cardiovascular disease, and diabetes (Burke *et al.*, 2008). As such, obesity has been described as a major worldwide public health concern and a priority for health intervention (World Health Organization; WHO, 2004). Improvements in physical health are seen with relatively small reductions in body weight (between 5% and 7%; Cummings, Parham & Strain, 2009). Modest weight loss, if maintained over time, is associated with improvements in physical health (Katz *et al.*, 2005), such as a reduction in blood pressure, improved cholesterol levels, and a decreased risk for type-2 diabetes (Klein *et al.*, 2004).

Adults with intellectual disabilities (ID) are at a significantly increased risk for physical health problems and morbidity compared to the general population. In addition to general health disparities, adults with ID have an equal, if not greater, risk of obesity compared to the general population (e.g., Emerson, 2005; Yamaki, 2005; Rimmer & Yamaki, 2006; Stancliffe *et al.*, 2011). Prevalence rates vary dependent on populations studied, sampling methods used, and geographic location. A recent large-scale population-based study in the UK reported that, for adults aged 25 years or older, 15% of men with ID were obese (compared to 19% in the general population) and 32% of women with ID were obese (compared to 23% in the general population; Bhaumik, Watson, Thorp, Tyrer & McGrother, 2008). Factors associated with higher levels of obesity within the adult ID population include being female, having a mild-moderate ID, living in the community, low physical activity levels, using psychotropic medication, having more friends and social opportunities, having Prader-Willi, Cohen, or Bardet-Biedl syndromes, and having hypertension (Bhaumik *et al.*, 2008; Melville, Hamilton, Hankey, Miller, & Boyle, 2007).

In a meta-analysis of 80 randomized controlled trials for weight loss in the general population for interventions that included a reduced-calorie diet, physical activity and/or weight loss medication, Franz and colleagues (2007) found that typical weight loss observed during the first 6-months ranged from 5% to 9% of starting body weight. In studies that included follow-up of participants up to 48-months, weight loss of 3% to 6% (of starting body weight) was maintained during this period. The results show that weight-loss interventions that include a reduced-calorie diet and physical activity are associated with moderate weight loss at six months and these losses can be maintained over the medium term. The Franz et al. meta-analysis results also suggested that weight-loss medication might enhance the maintenance of weight-loss.

A meta-analysis of interventions comparing diet and exercise to diet alone, found that diet combined with exercise produced a 20% greater initial weight loss and a 20% greater sustained weight loss after 1-year, compared to diet alone (Curioni & Lourenco, 2005). For the general population, multi-component interventions for weight loss are recommended internationally. For example, multi-component interventions for adults are identified in UK health guidance as the treatment of choice and are recommended to include a combination of a healthy diet and reducing energy intake, increasing physical activity levels or decreasing sedentary behaviour, and behaviour change techniques (National Institute for Health and Clinical Excellence; NICE, 2006).

We found two recent reviews of weight loss interventions for adults with ID (Hamilton, Hankey, Miller, Boyle, & Melville, 2007; Jinks, Cotton, & Rylance, 2011). Hamilton and colleagues' review focused on weight loss interventions that increased physical activity, involved carers, and used behavioural and health education/promotion techniques/principles. Eight studies were described in the

review. However, systematic review methods were not reported as being used and so it is possible that some evidence was missed. Jinks and colleagues conducted an integrative systematic review that described 12 studies. One study was predominantly qualitative in nature and explored client, carer, and staff satisfaction with the weight-loss programme that clients had attended. The remainder of the studies were quantitative in nature. Although systematic review methods were used, Jinks et al. excluded research published before 1998 because these studies were deemed as "…rather out-dated" (p. 461), without explaining in further detail why these studies were not included in their review. Both of the existing reviews concluded that successful weight loss may be achieved for adults with ID. However, no meta-analysis methods were used to provide an overall quantitative summary and all types of interventions (rather than specifically the internationally recommended multi-component interventions) were included.

The purpose of the present study was to address the limitations of the previous reviews by conducting a systematic review of all multi-component weight loss interventions for adults with ID, and to examine the evidence for outcomes using a summary meta-analysis.

Methods

Search Strategy and Data Collection

A computerized search of the Medline (PubMed), CINAHL (Cumulative Index for Nursing and Allied Health Literature), Web of Knowledge, PsycInfo, and the Cochrane databases, as well as Google Scholar and Scirus (for grey literature) was undertaken between January and February 2012, and updated in August 2012. The search terms used included international labels for intellectual disability (Intellectual disability OR Learning disability OR Learning difficulties OR Learning disorders OR

Mental Retardation OR Developmental Disability OR Mental Deficiency OR Mental

Disability OR Cognitive disorders OR Special Needs OR Mental Handicap) AND

weight loss (Obesity OR obese OR overweight OR weight OR weight gain OR

weight loss OR body mass index OR BMI OR morbid obesity). The titles and

abstracts of all papers identified in the initial search were read by the first author, to

determine whether the studies required further assessment. If a study reported

outcome data for weight loss in adults with ID, the study was obtained for further

assessment. In addition, the reference lists and the "related articles" feature (for

articles of a similar nature) of identified journal articles and review articles were

examined for further potential studies. Finally, all studies identified for the review

were included in citation searches to identify other related reports. This iterative

process continued until no more new studies were identified. All papers identified as

potentially relevant during this initial search phase were obtained and examined in

more detail.

The first author used a coding scheme (Appendix S) to code all of the studies

identified in the initial search. The inclusion criteria included: a) that participants

were adults, aged over 18 years old, (b) that they were reported as having an ID

supported with IQ data or a statement that they were in receipt of ID services, c) that

the intervention was multi-component in nature including two or more of the

following components: i) diet, ii) physical activity, iii) behaviour change techniques,

iv) health education/promotion materials, d) that the focus of the intervention was to

reduce weight/BMI, and e) that the studies reported Body Mass Index (BMI) or

weight data and a minimum of pre- and post-intervention data for at least one of these

variables. Exclusion criteria for studies included: a) the intervention was surgical

(e.g., gastric band surgery) or pharmacological in nature, or if these were combined

with other components, b) the study was not reported in the English language, and c) that interventions were single-cases or descriptions of programmes (with no outcome data) only.

The electronic and manual searches identified 8,433 possible publications. After the screening of titles, abstracts, and keywords, 43 papers remained for further assessment. A reliability check was conducted on a sample of 434 abstracts identified in the initial search. The results from a second reviewer, making the decision of whether or not a paper should be subjected to further detailed assessment, were compared to those of the first author and 100% agreement was obtained. The 43 studies that remained after the initial screening were coded by the first author and by the same second reviewer. Again, the significant decision was whether a study met the inclusion/exclusion criteria for the review. Initial agreement was high (97.06%) with disagreement about only one study, which was resolved after a brief discussion.

Of the 43 papers originally identified for the review, 32 papers were excluded, while 11 studies were identified for the review based on the inclusion/exclusion criteria. Two studies were later excluded because no suitable data or statistic was reported that allowed an effect size calculation for meta-analysis. One further report was excluded because only follow up data from another study already included in the review were reported. Therefore, eight studies were retained for the systematic review and meta-analysis. Figure 1 summarizes the study search and selection process.
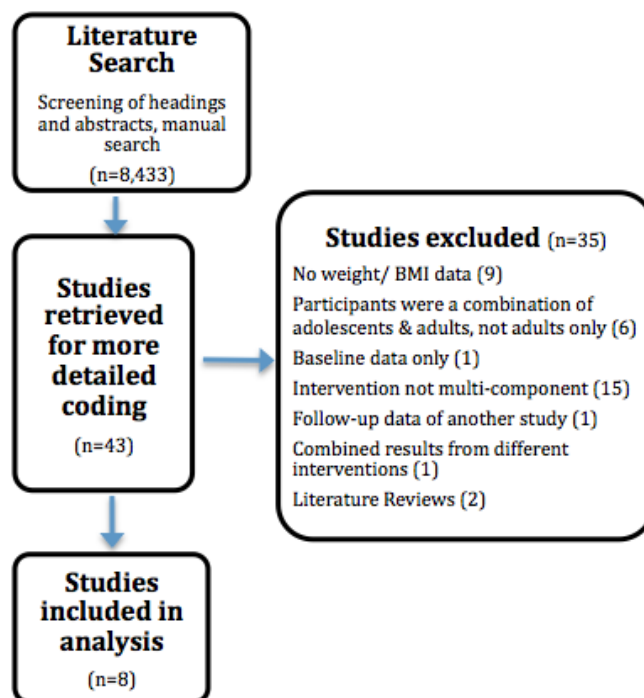
Figure 1: The search and selection procedure

The first author and a second reviewer independently extracted data on weight (kg), BMI, participant numbers, and length and type of intervention. Agreement was 100% for all data extracted from the eight original papers.

Quantitative data synthesis

Weight, measured in kilograms (kg) and BMI (kg/m^2) were the main outcomes of interest in the meta-analysis. BMI is a reasonably reliable indicator of adiposity (body fatness) and is commonly used as a method for measuring body fat, especially for population-based studies of obesity. BMI has also been found to be a reasonable indicator of adiposity for adults with ID (Temple, Walkley & Greenway, 2010). BMI is calculated by dividing a person's weight, measured in kilograms, by their height, measured in metres (and squared). People are classed as being underweight if their BMI is below 18.5 kg/m^2, of normal weight if their BMI is between 18.5-24.5 kg/m^2, overweight if BMI is between 24.5-30 kg/m^2, obese if their

BMI is between 30-40 kg/m^2, and morbidly obese if their BMI is above 40 kg/m^2

(World Health Organization [WHO] Expert Committee on Physical Status, 1995).

For the Bazzano *et al.* (2009) paper, it was necessary to calculate standard

deviations for the data, as none were provided. This was done using weighted-means,

based on the numbers of participants in the sample compared to the means, standard

deviations, and sample sizes of the other studies included in this review. For the

Chapman, Craven and Chadwick (2005) study it was also necessary to calculate the

post-intervention weight for participants, as these data were not reported in the paper.

It was possible to do this by calculating the average height of the group at baseline

using weight and BMI data. This average height was then used to estimate

participants' weight as a group post-intervention. This was possible as data were only

reported in the paper for the 38 participants who completed the intervention. Again,

standard deviations for these weight data were calculated using weighted-means as

previously described.

Data were entered into RevMan5.1 software (The Nordic Cochrane Centre,

2011) to assess if all studies were drawn from a population of studies with a common

mean effect size, (i.e., testing homogeneity). This was done using I^2 and the Q-

statistic, for all eight studies, utilizing the option for this analysis in the RevMan 5.1

software. I^2 indicates the amount of variance that can be explained by between-study

variance. Publication bias was assessed using funnel plots, of the mean difference and

the standard error of the mean difference for studies reporting BMI data (Figure 2)

and weight data (Figure 3) separately (Egger, Smith, Schneider, & Minder, 1997).
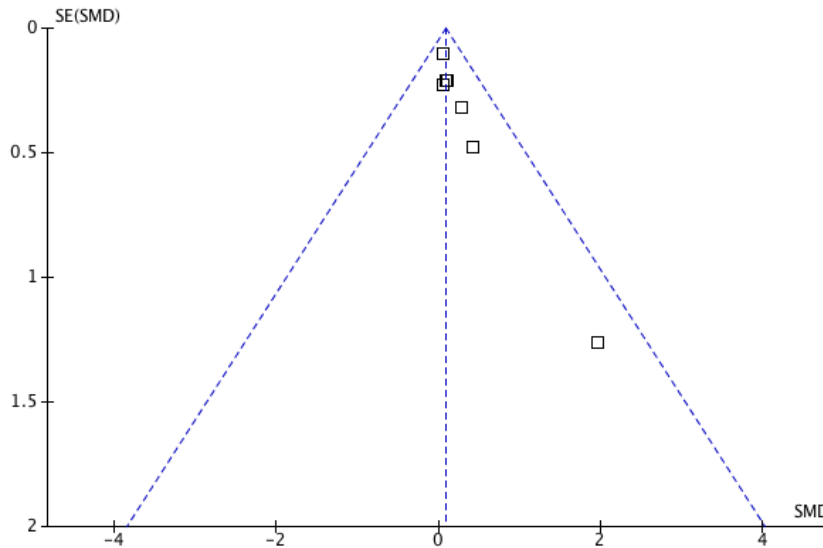
Figure 2: Funnel plot for BMI outcomes: standardized mean difference effect sizes are plotted against standard errors. The squares represent the studies in the analysis. The vertical line represents the population effect estimate and the diagonal lines represent the 95% confidence intervals.
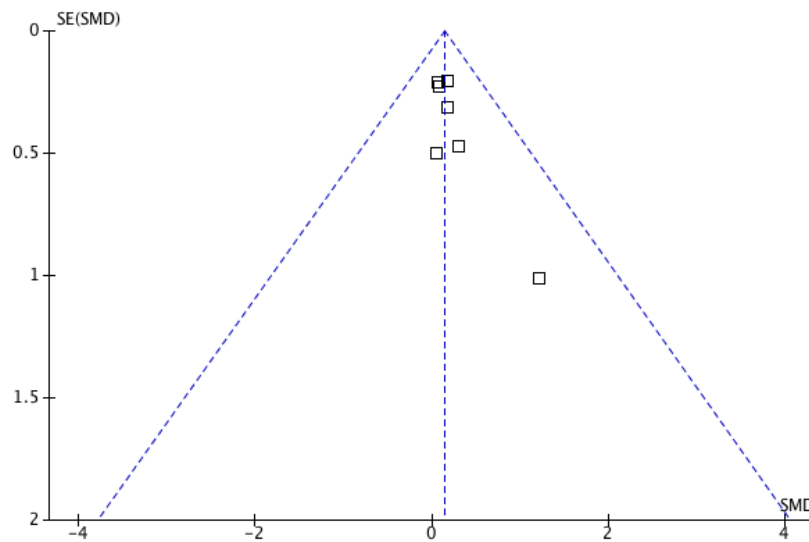
Figure 3: Funnel plot for weight loss outcomes: standardized mean difference effect sizes are plotted against standard errors. The squares represent the studies in the analysis. The vertical line represents the population effect estimate and the diagonal lines represent the 95% confidence intervals.

As only one of the studies was a controlled study, while the other seven were not, it was necessary to calculate the pre-post standardized mean difference effect sizes for each study to examine the effectiveness of weight loss interventions, rather than to use an effect size metric that took advantage of control group comparisons. For the controlled study, it was decided to only include data from the intervention group in the analyses, to compare like with like. The standardized mean difference effect sizes for weight loss interventions were calculated separately for weight loss (kg) and reductions in BMI (kg/m^2). We used the Hedges' g adjusted effect size measure (Hedges & Olkin, 1985), which is similar to Cohen's d, but includes an adjustment for small sample bias.

Results

Homogeneity

The Q-statistic was non-significant for both weight Q (5) = 1.67, p =.89, and BMI Q (6) = 6.34, p =.39, across the eight studies identified during the review process. This indicated that these studies could be combined for one common effect size. The between-study variance for weight (I^2 = 19.91%) and BMI (I^2 = 16.67%) were also calculated. These results suggest that only a small amount of variance could be explained by between-study variance. As a result, we used a fixed effects model for computing all effect sizes.

Publication Bias

The funnel plots (Figures 2 and 3) show that there is no evidence of publication bias. The data points for the studies are fairly symmetrical around the population effect size and both figures have the shape of a funnel.

Study Characteristics

Of the eight studies included in the review, four were conducted in the UK and four in the USA (see Table 1 for summary information). Settings included community-based programmes, programmes at resource or day centres, programmes at sheltered workshops, and those conducted in residential centres. Sample sizes ranged from 3 to 192 participants. For three studies, the participants' level of ID was not specified (Bazzano *et al.*, 2009; Bradley, 2005; Chapman *et al.*, 2005). For two studies (Marshall, McConkey, & Moore, 2003; Melville *et al.*, 2011) participants volunteered to take part and were judged, under UK law, to have the capacity to consent, making it likely that they had a mild-moderate impairment in intellectual functioning. Fisher (1986) reported that participants had mild-moderate ID, Mann, Zhou, McDermott & Poston (2006) reported participants having mild to moderate ID, and Croce (1990) reported participants as having severe levels of ID. None of the studies reported participants' individual IQ scores. Only the Melville *et al.*, study reported the proportion of participants (22.2%) who were prescribed obesogenic medication.

Interventions lasted between six weeks (Marshall *et al.*, 2003) and 12 months (Chapman *et al.*, 2005). On average, interventions lasted 23.88 weeks (*SD* = 16.30 weeks).

Table 1: Summary of studies included in the review and meta-analysis

Study	Study Location	*N* Enrolled	*N* Completed	Control Group	Intervention Components	Intervention Duration	Follow-up duration	Pre Intervention Weight (kg) Mean, (*SD*)	Post Intervention Weight (kg) Mean, (*SD*)	Pre Intervention BMI (kg/m^2) Mean, (*SD*)	Post Intervention BMI (kg/m^2) Mean, (*SD*)
Bazzano *et al.*, 2009	USA: community	68	44 Female 61.4% Male 38.6%	No	Health Promotion, Physical Activity	7 months	None	87.99 (18.91)*	86.82 (14.21)*	33.3 (6.24)*	32.8 (5.44)*
Bradley (2005)	UK: community	9	9 Female 100%	No	Health Promotion, Physical Activity	10 months	None	86.94 (15.35)	82.56 (12.72)	37.70 (7.093)	34.70 (6.39)
Chapman *et al.*, 2005	UK: resource centre	38	38 Female 43% Male 57%	Yes	Health Promotion, Diet, Physical Activity	1 year	6 years – see Chapman *et al.*, 2008	86.48 (15.02)	85.21* (19.31)*	34.89 (5.73)	34.57 (5.49)
Croce, 1990	USA: residential centre	3	3 Male 100%	No	Diet, Physical Activity	24 weeks	None	98.77 (5.53)	91.07 (4.65)	30.65 (1.86)	27.31 (0.55)
Fisher, 1986	USA: sheltered workshop	8	8 Female 100%	No	Physical Activity, Behavioural Self-control	8 weeks	4 weeks	69.00 (13.00)	68.40 (13.90)	No data available	No data available
Mann *et al.*, 2006	USA: community	324	192 Female 66.7% Male 33.3%	No	Health Promotion, Physical Activity	9 weeks	None	No data available	No data available	35.38 (6.85)	35.07 (6.59)
Marshall *et al.*, 2003	UK: day centres & community	25	25 Female 32% Male 68%	No	Health Promotion, Diet, Physical Activity	6 or 8 weeks	None	85.00 (19.4)	81.60 (17.8)	35.50 (5.9)	31.90 (5.4)
Melville *et al.*, 2011	UK: community	54	54 Female 59.3% Male 22 40.7%	No	Health Promotion, Diet, Physical Activity, Behaviour Modification	24 weeks	None	100.60 (26.80)	96.10 (26.90)	40.00 (8.03)	39.20 (8.20)

Only one study (Fisher, 1986) included a follow-up of weight-loss at the end of the intervention period, although this was rather short (four weeks after the end of the initial intervention). Chapman and colleagues (2005) did follow up the participants after six years but the results are published separately and not included in this review so as not to double count data from the same participants (Chapman, Craven, & Chadwick, 2008). Only one of the eight studies (Chapman *et al.*, 2005) made use of a non-intervention control group. The control group included people who attended day resource centres who were not receiving the intervention but who were mobile enough to stand on the weighing scales. The paper does not specify what the day centre programme offered in terms of activities to the control group. The remainder of the studies used a single group pre-post test design. None of the studies reported the fidelity of their interventions in their results.

Interventions

Six of the studies used health promotion/education as a component of their interventions. The topics covered varied across the different studies. Bazzano *et al.* (2009) held interactive health education sessions and focused on self-care, nutrition, fitness, chronic medical conditions, and frequently used medication. Bradley (2005) held healthy eating sessions, where participants were taught the importance of a healthy and balanced diet and how to maintain a healthy weight. In addition, Bradley conducted supermarket sessions, where participants visited supermarkets to discuss commonly purchased food items in terms of their nutritional content and also to teach participants how to interpret food labels. Chapman *et al.* (2005) provided health promotion materials to their participants, but no details on their content were provided in the published report. Mann *et al.* (2006) used the "*Steps to your Health Curriculum*" (University of South Carolina School of Medicine, 1997) modified

specifically for adults with ID by the authors, which emphasised the benefits of weight loss, a healthy diet and exercise, as well as teaching participants to communicate more effectively. Participants were also given the opportunity to visit local shops to identify healthy food choices. Marshall *et al.* (2003) used a modified version of the "*Activate Programme*", developed by the Health Promotion Agency of Northern Ireland in 1992 (Health Promotion Agency for Northern Ireland, 2009) to promote the benefits of healthy eating and exercise. Melville *et al.* (2011) used their health promotion sessions to emphasize the benefits of weight loss, physical activity and a healthy diet.

Five studies also focused on altering participants' diets. Bradley (2005), as part of the healthy eating sessions, gave participants the opportunity to taste new and healthy foods, such as fruit and vegetables, as well as providing advice on a healthy diet. The Chapman *et al.* (2005) and Marshall *et al.* (2003) interventions offered dietary advice to participants, as well as to those who supported them to live in the community. Chapman *et al.* (2005) offered advice on healthy food choices, while Marshall *et al.* (2003) also offered advice on healthy food choices while participants learned about different food groups. Croce (1990) and Melville *et al.* (2011) used daily energy-deficient diets, which were 500-kcal and 600-kcal lower than the recommended typical calorific allowance for adults respectively. In addition, the participants in the Melville *et al.* (2011) study were provided with personalised dietary prescriptions, which included recommendations on portion sizes.

All studies included a physical activity component. Four studies (Bradley, 2005; Chapman *et al.*, 2005, Mann *et al.*, 2006; Marshall *et al.*, 2003) offered participants advice on how to increase their physical activity levels. Bazzano *et al.* (2009) provided participants with one hour of supervised physical activity a week, for

the duration of the intervention. In addition, they developed a peer fitness video, which showed people with ID, who were peer-mentors in the programme, doing physical activity with a qualified physical activity instructor. Croce's (1990) intervention included participants taking part in one hour of aerobic exercise (using treadmills and stationary bicycles) on five days of the week for the duration of the intervention. Fisher's (1986) intervention included a walking exercise, where participants were told to walk each day, initially for 10 minutes for the first two weeks of the intervention, and the time spent walking was increased by an additional five minutes every fortnight, so that participants were walking for 30 minutes every day by the end of the intervention period. Melville *et al.* (2011) encouraged participants to do a minimum of 30 minutes of moderate intensity physical activity on five or more days of the week. In addition, participants were given pedometers and walking targets to increase the distance that they walked during the intervention period. Participants were also encouraged to spend less time engaging in sedentary activities, such as using computers or watching TV.

Four studies utilized behaviour modification and self-management techniques as part of their interventions. Bazzano *et al.* (2009) used peer mentors to model healthy behaviours. Participants' attendance in sessions, weight loss and completing the programme were rewarded with "incentives" for these achievements, but these were not specified in the report. Fisher (1986) asked participants to monitor their food intake, as well as their weight, on a daily basis, as well as noticing environmental events related to their eating behaviour, slowing their rate of eating and reducing the amount of food consumed. Mann *et al.* (2006) taught participants stress reduction techniques, as well as relapse prevention strategies. Melville *et al.* (2011) asked participants to set goals and to monitor their behaviour between sessions.

Interventions were led by a variety of different professionals, including dieticians (Bradley, 2005), physiotherapists (Chapman *et al.*, 2005), and nurses specialising in ID (Marshall *et al.*, 2003). One study used adults with ID as peer mentors to support the participants (Bazzano *et al.*, 2009).

Outcome Measures

Seven studies reported the change in participants' weight (measured in kg) between pre- and post-intervention or provided data to allow for pre-post changes to be established (Bazzano *et al.*, 2009; Bradley, 2005; Chapman *et al.*, 2005; Croce, 1990; Fisher, 1986; Marshall *et al.*, 2003; Melville *et al.*, 2011). All studies reported mean weight loss for participants over the intervention period. Weight loss between the pre- and post-intervention period ranged from -0.60kg to -7.70kg ($M = $ -3.48kg). These changes were not, of course, assessed in relation to a control group.

Seven studies reported the change in participants' BMI between pre- and post-intervention or provided data to allow for pre-post changes to be established (Bazzano *et al.*, 2009; Bradley, 2005; Chapman *et al.*, 2005; Croce, 1990; Mann *et al.*, 2006; Marshall *et al.*, 2003; Melville *et al.*, 2011). All studies reported mean BMI reduction for participants following the intervention period. Change in BMI between the pre- and post-intervention period ranged from -0.32 to -3.34 kg/m^2 ($M = $ -1.36 kg/m^2). Again, these changes were not in relation to a control group.

Quantitative Data Synthesis

Study or Subgroup	Weight	Std. Mean Difference IV, Fixed, 95% CI	
Bazzano 2009	12.7%	0.08 [-0.33, 0.50]	
Bradley 2005	2.5%	0.42 [-0.51, 1.36]	
Chapman 2005	11.0%	0.06 [-0.39, 0.51]	
Croce 1990	0.4%	1.95 [-0.52, 4.42]	
Fisher 1986		Not estimable	
Mann 2006	55.3%	0.05 [-0.15, 0.25]	
Marshall 2003	5.7%	0.28 [-0.35, 0.90]	
Melville 2011	12.4%	0.10 [-0.32, 0.52]	
Total (95% CI)	100.0%	0.09 [-0.06, 0.24]	
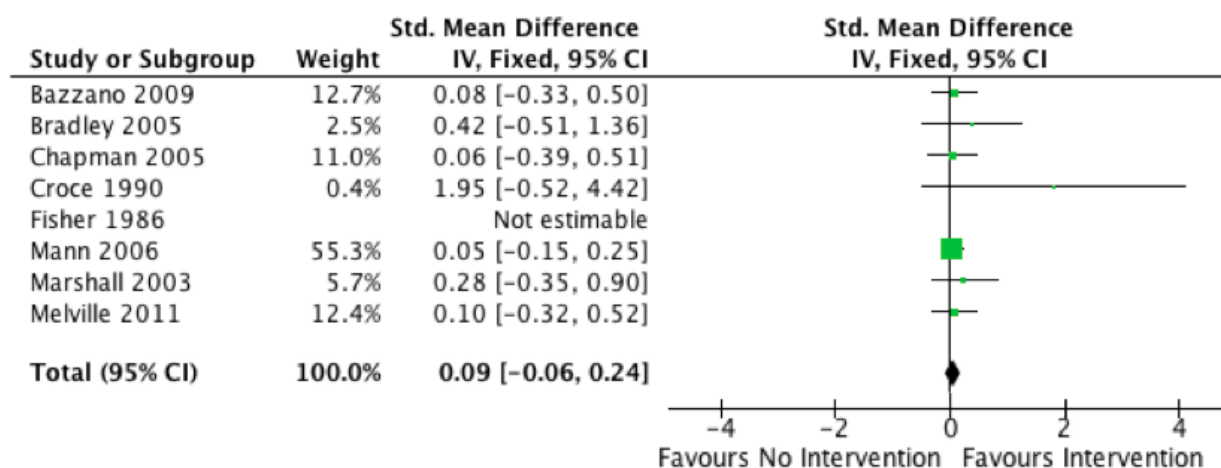
Figure 4: Forest plot of pre-post mean differences and 95% confidence intervals (CI) for change in BMI.

Figure 4 summarizes the results of the meta-analysis of the effect of multi-component interventions on participants' BMI from pre- to post-intervention. Seven papers reported enough information for inclusion in the meta-analysis. For the calculation of an overall weighted effect size, the weightings applied to the studies included in the analysis were based on the inverse variance of the study estimate of each included study (Borenstein, Hedges, Higgins & Rothstein, 2009). The largest weighting (55.30%) in this analysis was for the Mann *et al.* (2006) study, while the smallest weighting (0.40%) was for the Croce study. None of the seven individual studies revealed a change in BMI (kg/m^2) that was statistically significant between pre- and post-intervention (in all cases, the 95% CI contained zero), although all seven studies did report group mean reductions in BMI. The largest effect sizes (between pre- and post-intervention) were seen in the Croce (Hedges' $g = 1.95$) and Bradley (Hedges' $g = 0.42$) studies. The smallest effect sizes were seen in the Chapman *et al.* (Hedges' $g = 0.06$) and Mann *et al.* (Hedges' $g = 0.05$) studies. The

overall results showed a meta-analytic pre-post effect size of 0.09 (95% CI -0.06, 0.24) indicating that multi-component interventions for weight loss in adults with ID did not result in a statistically significant pre- to post-intervention reduction in participants' BMI.

Study or Subgroup	Weight	Std. Mean Difference IV, Fixed, 95% CI	Std. Mean Difference IV, Fixed, 95% CI
Bazzano 2009	26.2%	0.07 [-0.35, 0.49]	
Bradley 2005	5.3%	0.30 [-0.63, 1.23]	
Chapman 2005	22.7%	0.07 [-0.38, 0.52]	
Croce 1990	1.2%	1.21 [-0.77, 3.18]	
Fisher 1986	4.8%	0.04 [-0.94, 1.02]	
Mann 2006		Not estimable	
Marshall 2003	11.9%	0.18 [-0.44, 0.80]	
Melville 2011	28.0%	0.17 [-0.24, 0.57]	
Total (95% CI)	100.0%	0.13 [-0.08, 0.35]	

Favours No Intervention   Favours Intervention

Figure 5: Forest plot of pre-post mean differences and 95% confidence intervals (CI) for change in body weight in kg.

Figure 5 summarizes the results from the meta-analysis of the effect of multi-component interventions on participants' pre-post changes in weight (kg). Seven papers reported enough information for inclusion in the meta-analysis. For the calculation of the overall weighted effect, the weightings applied to the studies included in the analysis were again based on the inverse variance of the study estimate of each included study (Borenstein, *et al*., 2009). The largest weighting (26.20%) in this analysis was for the Bazzano *et al.* (2009) study, while the smallest weighting (1.20%) was for the Croce study. None of the effect sizes for change in weight (kg) between pre- and post-intervention in individual studies were statistically significant, although all seven studies did again report group mean reductions in weight. The largest effect sizes between pre- and post-intervention were seen in the Croce (Hedges' $g = 1.21$) and Bradley (Hedges' $g = 0.30$) studies. The smallest effect

size was seen in Fisher (Hedges' $g = 0.04$) study. The results show a combined pre-post effect size of 0.13 (95% CI -0.08, 0.35 kg). This meta-analytic effect was also not statistically significant.

Discussion

A systematic review identified eight studies of multi-component weight loss interventions for adults with ID. Only one study included adults with severe ID as participants, while the remainder of the studies had participants with mild-moderate ID. Sample sizes ranged from 3 to 192 participants, and intervention periods ranged from 6 weeks to 12 months. Only one study utilized a non-intervention control group and only one research group followed-up participants beyond the intervention period. All studies included a physical activity component to their intervention, while six included a health promotion/ education component; five studies addressed participants' diets, and only four studies utilized behaviour modification and self-management techniques.

None of the individual studies revealed a standardized mean difference effect size that was statistically significant between pre- and post-intervention, for change in weight or in BMI. Using meta-analytic methods, we found very small effect sizes for pre-post change in weight and BMI following multi-component interventions for weight loss in adults with ID. The meta-analytic estimates for weight loss and reduction in BMI were also not statistically significant. For weight loss, the meta-analytic results represent a pre- to post-intervention mean difference of 3.18 kg (95% CI -0.36, 6.73 kg), and this is substantially lower compared to meta-analyses of multi-component weight-loss interventions (of a similar duration) in the non-ID population,

where weight loss following intervention ranges from 9.90 to 13.00 kg (e.g. Curioni & Lourenco, 2005; Franz *et al.*, 2007).

Given that this is, as far as we are aware, the only meta-analysis to date to assess the putative effectiveness of multi-component interventions for weight loss in adults with ID, we cannot draw comparisons with the results of previous reviews. We have addressed the main limitations identified in the two previous reviews of evidence on weight loss interventions for adults with ID in three ways: conducting a systematic review without date limits for our searches, focusing on evidence relating to internationally recommended weight loss interventions (i.e., multi-component interventions only), and conducting a meta-analysis of the available data.

A number of cautions need to be emphasized. First, the number of studies included in our analysis is small. Hamilton and colleagues (2007) also only had eight studies in their review, while Jinks and colleagues' (2011) review contained 12 studies. Although research to develop effective weight-loss programs for adults with ID has been conducted for more than three decades, very few studies exist. A second methodological limitation of the present review was that no analysis was conducted on the effect of moderator variables on intervention outcomes because of the small number of available studies. This should be a priority for future research when more studies are published within this area.

Perhaps the most serious limitation is the quality of the studies that we reviewed. We did not carry out formal quality evaluation of studies prior to inclusion in the review. If we had done so, no evidence would have been included. No studies randomly allocated participants to intervention groups, and only one study (Chapman *et al.*, 2005) made use of a control group. Therefore, none of the studies included in the present study met the highest-level criteria of methodological rigor (Type I studies

- Nathan & Gorman, 2002). Even in the controlled study, the methodological rigor was limited. Chapman et al's (2005) control participants on average had a lower starting weight and BMI than the intervention group. In addition, the control and intervention groups were not matched on important characteristics, such as age, gender, ability level, obesogenic medication use, or fitness levels. Only one of the studies reported on follow-up data (Chapman et al., 2008). Therefore, it was not possible to assess if the weight losses observed during the interventions were maintained in the longer-term. Only one study (Melville *et al.*, 2011) reported the number of participants who were prescribed obesogenic medication. As many medications influence the body's metabolism, this is an important factor that should be taken into consideration when designing and evaluating weight-loss interventions for adults with ID. None of the studies reported the fidelity of their interventions. Adherence (or the lack of it) to an intervention could influence their effectiveness and therefore should have been noted. Two studies reported high attrition rates. Bazzano and colleagues' study reported that of the 68 participants who attended at least an initial session, 44 participants completed the intervention. The authors reported that the participants who attended the initial session and pre-intervention assessments were similar in initial weight to participants who completed the programme. However, they did not report if these participants were similar on other important baseline characteristics. Mann and colleagues' study reported that 324 participants took part in the intervention and had some data reported, 66 did not have a follow up BMI, which represented a 20% attrition rate. Other participants were removed as a result of having missing data or having changes in BMI, which seemed to be "unreasonably large" (pp. 66). The authors failed to report if participants who completed and failed to complete the programme were similar or dissimilar on

important characteristics, such as starting weight/ BMI, gender, age, level of ability, and residential settings.

The analyses conducted for the present paper focused on pre-post changes in BMI and/or weight. There is an urgent need for studies that include control groups so that these changes can be contextualized. Specifically, it is possible that obese individuals with ID receiving no active intervention may continue to increase their BMI/gain weight over time. In that context, even small reductions associated with intervention might then represent a positive outcome. Equally possible is that weight/BMI in obese adults with ID might tend to naturally decrease over time. In that context, the results of the present review would be more disappointing. Although the present results may appear to be disappointing in terms of evidence for multi-component weight loss interventions in adults with ID, it would be premature to dismiss the intervention models developed to date. Refinements are needed, but more importantly better research designs are required to provide a more rigorous test of existing interventions.

Multi-component weight loss interventions for people with ID are complex interventions. This complexity derives from having several interacting components in the interventions themselves, and as a result of the difficulty of standardising the design and delivery of the intervention in a group of people who rely heavily on others for support. In 2000, the United Kingdom's Medical Research Council (MRC) published guidelines for the development and evaluation of such complex interventions, and these guidelines were updated in 2008 (Craig et al., 2008). The guidelines suggest that when developing complex interventions, the intervention should be based on a coherent theory. It is not clear from the studies included in this review whether this was the case. For example, a weight loss intervention for adults

with ID may rely partly on appearance motives. However, if no preliminary research has established if adults with ID are sensitive to their appearance as a motivating factor, we cannot be confident that interventions relying on this feature will succeed.

Very little research has focused on the motives of adults with ID to engage in weight loss interventions, compared to the health promotion literature for the non-ID population. Clearly more research is needed in this area to assess if adults with ID do feel under social pressure to lose weight, or if indeed they are motivated by body image. Similarly, more preliminary research may be needed to address why adults with ID engage in unhealthy behaviours and do not engage in healthy behaviours (e.g., engaging in physical activity, and eating healthy food). Such research would inform the design of weight loss and other healthy lifestyle interventions.

The MRC complex intervention guidelines (Craig *et al.*, 2008) also state that piloting and feasibility work is needed to be confident that the intervention can be delivered as intended. This is especially important when trying to implement an intervention when participants live in different residential settings. For example, asking participants to eat more healthy food in principle seems relatively straightforward, but without taking into account the budgetary restraints faced by staff in residential services, the intervention may be likely to fail. Complex interventions rarely occur in isolation. Therefore, researchers need to take into account the possible interactions between the "system" (where the intervention is occurring) and the intervention itself, when designing and evaluating the intervention (Shiell, Hawe & Gold, 2008).

When evaluating interventions it is important to compare the effectiveness of the intervention to usual care and, ideally, this should be done using a parallel group randomized controlled trial. Cluster randomization may be appropriate for group-

based interventions (Eccles, Grimshaw, Campbell & Ramsay, 2003). At the very

least, a control group who have not received any intervention should be included. In

the studies included in this review, only one utilized a control group for comparative

purposes. It is also important to monitor the delivery of the intervention, to ensure that

all participants received the intervention in the same way. Again, none of the studies

included in this review reported assessing treatment fidelity. Economic evaluations of

interventions are also useful especially in terms of informing decision-makers. Again,

none of the studies included in this review reported the cost of their intervention or

how it compared to the cost of usual care.

Implications for Research, Policy and Practice

Despite the limitations outlined above, the present analysis suggests that

multi-component weight loss interventions for adults with ID result in small changes

in BMI and weight. However, these changes are not statistically significant. Modest

weight loss may ultimately mean the prevention of weight gain. Guidelines have

suggested that this approach may be an alternative approach to aiming for major

weight loss to meet one's ideal weight (National Audit Office, 2001; Lean, 2003).

Small reductions in starting body weight, between 5 and 7%, are associated with

significant decreases in obesity-related co-morbidities (Cummings *et al.*, 2009).

Interventions should also take into account the unique needs of adults with ID.

Adults with ID quite often need the support of staff or family members when planning

meals, cooking, shopping, and accessing leisure facilities for physical activity.

Hamilton *et al.*'s (2007) review reported mixed results when including family

members or paid staff in weight loss interventions for adults with ID. Generally,

participants with ID who have carer support do slightly better in weight loss

programmes, perhaps through improved attendance, but there are few studies

addressing this important factor. Perhaps adults with ID would be more motivated to

engage in healthier lifestyles if their carers, both paid staff and family members,

support them to do so and themselves value the benefits of a healthy lifestyle. This

could be done by raising awareness of healthy lifestyles with carers as well as

including carers in the planning stages of weight loss interventions. Adults with ID

may also have mobility problems, and may take medication that is obesogenic. As a

result, interventions should be designed that can address all of these potential barriers

to weight loss for adults with ID. Only one of the included studies in this review

included adults with severe ID. Not only is research needed to assess the effectiveness

of multi-component interventions for this group, but also the preliminary work, as

mentioned previously, is needed to ensure the effectiveness of these interventions.

Policies for services, both residential and day opportunities, for adults with ID

need to ensure that the barriers mentioned previously do not prevent adults with ID

from living healthy lifestyles. Policies also need to ensure that adults with ID are

offered "healthy choices" in terms of their diet and for suitable health-promoting

physical activities. National health education campaigns which promote physical

activity and a healthy diet for the general population also need to make sure that they

are accessible not only to adults with ID but also to other disadvantaged groups within

society.

Chapter 5. Longitudinal changes in physical health, mental health and challenging behaviour in adults with ID living in residential settings.

Abstract

Background   Adults with intellectual disabilities (ID) are at an increased risk for physical health problems, mental health problems and problem behaviour compared to the general population. The main aim of the present study was to evaluate the changes in physical health as a result of the service implementing an action research methodology, as well as exploring the associations between improvements in physical health and changes in mental health problems and challenging behaviour in adults with ID.

Methods   Data on physical health (using a health checklist), mental health, problem behaviours, adaptive behaviour (using standard measures) and physical activity (using a proxy diary format) were collected on 80 adults with ID aged 18-65 at Time 2 (T2), approximately 18-months after Time 1 (T1), and after the service had implemented a number of organisation-wide changes which aimed to improve physical health. The adults resided in specialist residential services for individuals with ID and additional complex needs.

Results   The results showed that between T1 and T2, participants had significantly fewer signs and symptoms of physical health problems, had significantly improved their BMI categories and had significantly improved their physical activity levels. ANCOVA models, to examine associations over time between changes in physical health and changes in mental health and behaviour problems, revealed that improvement in BMI between T1 and T2 was associated with less stereotyped behaviour at T2. None of the other physical health grouping variables entered as covariates at T1 were significant predictors of mental health or challenging behaviour at T2.

Conclusions   The majority of participants improved their physical health between T1 and T2. The results show the benefits of using audit data in order to target areas of clinical governance that need to be addressed. Future research needs to focus on the longitudinal changes in health, as well as the longitudinal relationship between physical and mental well-being.

Key words: adults, physical health, mental health, problem behaviours, intellectual disabilities, action research, associations.

In general, adults with intellectual disabilities (ID) experience worse health outcomes compared to adults without ID. There are numerous, often multifactorial, reasons for this, including genetic and biological factors related to the cause of ID, but also wider social determinants of health, such as education, housing, deprivation, and lower levels of health literacy or poor service outcomes. There is also a correlation between the severity of ID and life expectancy (median life expectancies of 74.00, 67.60 and 58.60 years for people with mild, moderate and severe ID respectively; Bittles, Petterson, Sullivan, Hussain, Glasson & Montgomery, 2002). Historically, adults with ID had shorter life expectancies compared to people without ID. However, this trend is now changing, with people with ID in general living longer (Haverman, Heller, Lee, Maaskant, Shooshtari & Strydom, 2010), and so more adults with ID are experiencing the same age-related illnesses seen in adults without ID. For example, the incidence of cancer amongst people with ID is rising (Sullivan, Hussain, Threlfall & Bittles, 2004), and it is likely that the prevalence of other long term conditions, such as type 2 diabetes, heart disease, and dementia will also increase.

In addition to physical health problems, as outlined above, research suggests that adults with ID experience the full range of mental health problems as adults without ID. In some instances, the prevalence of mental health problems is higher amongst adults with ID (e.g., Borthwick-Duffy & Eyman, 1990; Deb, Thomas & Bright, 2001a, b; Gustafsson & Sonnander, 2004; Smiley, 2005). The most common mental health problems in adults with ID are signs of depression, anxiety or adjustment problems, while problem behaviours such as aggression, self-injurious and stereotyped behaviours are also common (Gustafsson & Sonnander, 2004).

Existing research in the ID and general populations suggests that physical and mental well-being are related. For example, in the general population, chronic

physical health problems, such as asthma, angina, diabetes and arthritis are associated with co-morbid depression for 9.32-23.13% of the population (Moussavi, Chatterji, Verdes, Tandon, Patel & Utsun, 2007). Patients with cancer also experience psychological comorbidities, such as depression (22%), anxiety (38%) and post-traumatic distress (12%; Mehnert & Koch, 2008). Findings from ID research also suggest physical-mental health associations. For example, Deb and colleagues (2001a) found that adults with ID who had physical disabilities had higher rates of psychiatric illness, compared to those with ID without a physical disability.

Although there are cross-sectional studies of the physical-mental health associations in samples with ID, longitudinal designs are rarely used. Such designs are needed to be able to clarify directions of effects. In fact, there have been few longitudinal studies of physical health in the ID field irrespective of investigators' interest in the relationship between physical and mental health. Evenhuis (1997) reported longitudinal changes over a 10-year period in physical health for 70 older (mean age of 70 years (range 60-92) in 1983) individuals with ID in Holland. For example, over the 10-year period: 15 participants (29%) developed urinary incontinence; the development of endocrine disorders was also common with 11 females and 1 male developing type II diabetes and 3 females and 1 male developing hyperthyroidism; and eight men (31%) and eight females (18%) were diagnosed with malignancies.

Ashaye, Fernando, Kohen, Mathew and Orrell (1998) described the changes in physical health over a 5-year period for older adults with ID, as they moved from long-stay institutions into the community, in the USA. Ashaye and colleagues reported that participants' mobility, continence, vision, hearing and communication all worsened. Other researchers have gathered data on the incidence of physical health

problems over shorter periods. For example, Cooper *et al.,* (2006) described the

occurrence of new health problems during a 1-year period through screening of

medical notes. Cooper *et al.* described the presence of new physical health problems

in relation to the ICD-10 (WHO, 1992) classification of diseases. For example, 21

(42%) developed eye conditions; 26 (52%) developed problems with the ear; 15

(30%) developed circulatory problems; 9 (18%) developed skin conditions and 16

(32%) participants developed musculoskeletal problems. In adults without ID, during

a 3-year longitudinal study, 39.14% of adults were found to have a new physical

health condition (Rodin & McAvay**,** 1992).

The primary aim of this study was to evaluate the changes in the physical

health of participants as a result of raising awareness (within the residential service)

of the physical health needs of this group of clients. After data on physical health

were collected at Time 1, the data were summarized for, and distributed to, each

residential unit within the service. As a result of the data at Time 1, improving

physical health was a priority for the service's clinical governance for the duration of

the 18-month period. A range of initiatives was implemented by the service provider,

such as employing a dietician, activity co-coordinators for each residential unit

(whose responsibilities were to increase physical activity levels as well as other

meaningful activities), staff training on the benefits of a healthy lifestyle, improved

relationships with local health care providers and health promotion for participants.

This was not an intervention put in place by the authors and as such is a "natural

experiment" of the potential benefits of raising awareness by sharing audit-type data

with residential services. This intervention follows an 'Action Research'

methodology. Action research is an approach is an approach typically used to improve

conditions, practices and outcomes in healthcare settings (Lingard, Albert &

Levinson, 2008; Whitehead, Taket & Smith, 2003). Action research involves systematic data collection in order to improve an organisation's practice, which in turn improves outcomes for service users and staff (Whitehead *et al.*, 2003).

We could find no studies focused on participants with ID in which the longitudinal relationship between physical and mental health was reported. Neither could we find any studies that focused on improvements in mental health and challenging behaviour as a result of improving physical health. The secondary aim of the present study was, therefore, to explore the longitudinal associations over an 18-month period between physical health, mental health and problem behaviours in adults with ID.

Physical health information was captured through a health check methodology, physical activity using a diary method, and mental health and problem behaviour data from standard rating scales.

Method

Service Setting

Data were collected from one service provider organisation. The service consisted of 15 residential settings (11 on a shared site and 4 in the community), as well as a small specialist ID hospital. The services were all located across North-East Wales and North-West England (UK). The service provided care for adults with ID who also have additional needs, such as mental health problems, physical health problems, or problem behaviours. All adults with ID supported by the service were eligible for participation in the research. The number of service users per setting ranged from 1 to 17, with a mean of 10.4 individuals per setting.

Participants

Ninety five participants took part in the study at Time 1 (T1) and these

participants are previously described in Chapter 3. Overall, the sample at T1 consisted

of 61 (64.21%) males and 34 (35.79%) females. Their ages ranged from 20 years to

65 years (M=41.1, SD= 10.7). Aetiology of ID was unknown for 74 participants,

while five had Down syndrome recorded in their file and one participant each had the

following causes of ID recorded: Rett syndrome, Prader-Willi syndrome, Turner

syndrome, Fragile X syndrome, Oral-Facial-Digital syndrome, Ring 13 syndrome,

Moebius syndrome, Phenylketonuria, meningitis as a child, and cyanosis at birth.

Thirteen participants had a diagnosis of autism recorded on their file alongside their

ID. Forty four (46.32%) of the participants lived in residential settings with seven or

more other people, while the other 51 (53.68%) participants lived in residential

settings with fewer than seven other people. Fifty eight (61.05%) participants had

moderate to severe levels of deficits in adaptive skills (see Measures), with the

remainder having mild deficits to average adaptive skill functioning. No IQ data were

available for full confirmation of ID diagnosis, but all participants were

administratively defined as being in receipt of ID services.

Longitudinal data were collected from 80 adults with ID approximately 18-

months later (T2). Overall, the sample at T2 consisted of 51 (63.75%) males and 29

(36.25%) females. Their ages ranged from 22 years to 65 years (M=43.08, SD=

10.67). Twelve participants had a diagnosis of autism recorded on their file alongside

their ID. Thirty seven (46.25%) participants lived in residential settings with seven or

more other people, while the other 43 (53.75%) participants lived in residential

settings with fewer than seven other people. Fifty six (70.00%) participants had

moderate to severe levels of deficits in adaptive skills (see Measures), with the

remainder having mild deficits to average adaptive skill functioning. Between T1 and

T2, eight people had left the service, two people had passed away, two people were

over the age of 65 years old, and 3 people's capacity to consent had changed and we

were unable to arrange proxy consent or Best Interests meetings for these participants.

No significant differences were found, during comparison, on any of the demographic

variables described above between the sample followed up at T2 and the sample lost

to follow-up between T1 and T2. Thus, the sample for whom longitudinal data were

collected appeared to be reasonably representative of the initial sample.

Measures

Six measures were included in the study.

Adaptive Behavior:

To measure the adaptive skill level of participants, the Adaptive Behavior

Assessment System (ABAS-II; Harrison & Oakland, 2003) was used (Appendix G).

The ABAS-II is a comprehensive norm-referenced measure that assesses individuals'

adaptive skills and practical independent functioning, as well as their interactions with

others within the community. It is suitable for use from birth to 89 years of age.

Raters score each item using a 4-point Likert-type scale. The choices are: *is not able,*

never or almost never when needed, sometimes when needed, and *always or almost*

always when needed. The Global Adaptive Composite (GAC) and domain scores

have a mean of 100 and a standard deviation of 15. The lowest possible GAC score is

a standard score of 40 for all forms and all age groups. Internal consistency

(Cronbach's Alpha = 0.98-0.99), inter-rater reliability and content validity (0.78-0.98)

are all reported as good (Harrison & Oakland, 2003).

Physical Health:

Specifically developed for adults with ID, the "OK Health Check" (Matthews,

1997) is a checklist to identify and assess physical health needs (Appendix H). The

OK Health Check identifies symptoms relating to all of the bodily systems, including

the gastrointestinal, respiratory, cardiovascular, and neurological systems, as well as recording dental disease, epilepsy, mental health problems, and sensory impairments. The OK Health Check also signifies when reviews (e.g., of medication) and screening (e.g., breast, cervical) are required. The 123 items are answered using *Yes; No; Don't Know* and space is provided for additional information at the end of each sub-section. Inter-rater reliability (between medically trained and non-medically trained staff; $r=$ 0.92) and construct validity are reported as good (Matthews, 1997) and the checklist is widely used within community settings for screening purposes (Gates, 2006).

The OK Health Check data were summarized to provide the following information:

- *Physical Health Total Number of Signs and Symptoms:* total number of physical health signs and symptoms identified as present from the "OK Health Check"

- *Body Mass Index (BMI)* was calculated using the formula BMI = weight (kg)/height^2 (m^2). BMI status was coded as underweight ($<$18.5 kg/m^2), normal (18.6-24.9 kg/m^2), overweight (25-29.9 kg/m^2), obese (30-39.9 kg/m^2) and morbidly obese ($>$40 kg/m^2) (World Health Organization, 2000). Additionally, participants were coded as overweight/obese/morbidly obese vs. underweight/normal weight (i.e., a dichotomous code for obese vs. not obese).

Mental Health:

The Health of the Nation Outcome Scales (HoNOS-LD; Roy, Matthews, Clifford, Fowler & Martin, 2002; Appendix I) was adapted for use with adults, aged 18-65, with an ID and provides a method of measuring change in problem behaviours (such as aggression towards others or self), functioning (such as attention, concentration, memory, communication), mental health problems (such as changes in

mood) and physical health problems (such as physical problems, seizures). The

HoNOS items are scored on a scale of 0-4 (*0= no problem; 1= mild problem; 2=*

moderate problem; 4= severe problem) with the highest possible score being 72. The

eighteen items have good validity and reliability and the measure is viewed as

acceptable by clinicians (Roy *et al.*, 2002).

The Reiss Screen for Maladaptive Behavior (RSMB; Reiss, 1988) is a

screening instrument for adults with ID (Appendix J). The RSMB is informant based,

and each of the 38 items is scored as: *no problem, problem or major problem.* The

subscales measure symptoms of Aggression, Autism, Psychosis, Paranoia, Depression

(B) Behavioral symptoms, Depression (P) Psychological symptoms, Dependent

Personality, and Avoidant. Each subscale has a threshold score of nine, with scores of

nine or above indicating the presence of a mental health disorder. Good internal, inter-

rater, and test-retest reliability (Reiss, 1988; Rojahn, Warren & Ohringer, 1994) as

well as good criterion and concurrent validity have been reported (Reiss, 1988).

Behaviour Problems:

To measure behaviour problems we used the Behavior Problems Inventory-

Short Form (BPI-S) (Rojahn *et al*., 2012 a, b; Appendix K). The BPI-S is a 30-item

scale consisting of the three subscales: Self-Injurious (8 items), Stereotypic (12 items)

and Aggressive/Destructive behaviours (10 items). The BPI-S uses two Likert rating

scales per item, a seven-point frequency scale (*0=never; 1=fewer than once a month;*

2=about once a month; 3=about once a week; 4=about once a day; 5=about once

per hour; 6=more than once per hour; 7=once per minute or more), and a three-point

severity scale (*1=mild; 3=moderate; 9=severe*). A weighted score for each item can

be obtained by multiplying the frequency and severity scores. When comparing the

BPI-S to the full BPI-01 (Rojahn *et al.,* 2001) the sensitivity was reported to be high,

as were the correlations between the subscales for both the BPI-01 and the BPI-S

(Rojahn *et al.,* 2012b).

We previously (in Chapter 3) calculated Cronbach's alpha using the frequency

scores for the three behaviour domains of the BPI-S. The Self-Injurious Behaviour

(SIB) scale had poor internal consistency (Cronbach's alpha =.45), but internal

consistency for the aggressive/destructive behaviour scale (Cronbach's alpha =.83)

and stereotyped behaviour scale (Cronbach's alpha =.77) was good. It was therefore

decided to score SIB as a dichotomy (presence of any SIB vs. absence of SIB). In the

analyses reported below, the aggressive/destructive and stereotyped dimensions of

behaviour problems were scored on the basis of frequency ratings, with SIB scored as

a dichotomous present/absent variable.

Physical Activity:

The International Physical Activity Questionnaire (IPAQ; Craig *et al.*, 2003)

comprises four questionnaires, with long and short versions for use by either

telephone or self-administration. The questionnaires can be used to obtain

internationally comparable data on health-related physical activity. Extensive

reliability and validity testing was conducted across 12 countries and results show

acceptable psychometric properties to be used for 18-65 year old adults in diverse

settings (Craig *et al.*, 2003). The IPAQ is also suitable for national population-based

prevalence studies of participation in physical activity. In the present study, a proxy

respondent version (IPAQ-pr; Appendix A) based on the IPAQ was used. The process

of developing the IPAQ-pr is outlined in Chapter 2. This measure assesses how many

minutes a participant spent participating in physical activity, of different intensities,

during a one-week long period. The IPAQ-pr has strong criterion validity between

data extracted from the IPAQ-pr when compared to the accelerometer (Chapter 2).

The IPAQ-pr has very good criterion validity when measuring the association between the two categorical variables (meeting or not meeting WHO recommended physical activity levels; $\kappa_c = 0.82$, $p = .001$, 95% CI 0.48, 1.16). The IPAQ-pr has excellent criterion validity when measuring the association between time (hours) spent engaged in physical activity over a seven-day period ($r_S = .958$, $p < .001$).

All participants' physical activity levels were assessed during the same one-week period (i.e. at Time 1 and Time 2) to avoid confounding factors. However, as T1 and T2 differed by 18-months, the times of year when the IPAQ-pr was completed were different (T1 autumn, and T2 spring).

Support staff completed the IPAQ-pr. The IPAQ-pr allowed support staff to record the minutes spent by participants doing physical activity of different intensities, in the morning, afternoon, and evening each day for seven days. Examples of activities that met these different intensity levels were given to support staff, as well as an example of how to complete the IPAQ-pr. Support staff were also instructed to complete the IPAQ-pr at the end of each segment of the day (e.g. morning) and that the staff member who had been working closely with the participant during that time period should be the respondent. This is a different method of recording physical activity to the original IPAQ, which requires people completing the IPAQ to recall physical activity levels up to a week later.

Information from the IPAQ-pr was coded in terms of whether participants met the WHO guidelines (2000) for physical activity (>30 minutes of moderate intensity physical activity on ≥5 days of the week).

Procedure

The procedure was identical for the study at both time points. The study was subject to ethics and governance review by the School of Psychology, Bangor

University and approved by the senior management team of the service provider. Five

of the measures were routinely completed for each adult with ID on entering the

service and were updated at least annually as part of the review process. Informed

consent was requested for these data to be collected and used for research purposes.

The measures were completed by suitably trained staff, including clinical

psychologists and clinical nurse specialists. The only exception being the IPAQ-pr,

which was a measure added for the purpose of this study and was completed by

support staff who were in daily contact with the participants with ID.

Information sheets were given to participants (Appendix L) and to staff

(Appendix M). Functional assessments of capacity (Appendix N) were completed

with each participant by the first author using a best practice model based on the

Arscott, Dagnan and Kroese (1998) methodology. If the participants had capacity,

researchers asked for their informed consent (Appendix O). If the participant did not

have capacity to consent to the research, clinical staff and the first author completed a

best interests checklist (Appendix P). A proxy consent form (Appendix Q) was then

sent to relatives or services funding the placements (e.g., local government agencies

or health boards). If no response was received, a best interests meeting was arranged

to discuss the involvement of their person in the research (Appendix R). These

meetings included an invitation to family members, placing agencies, and

independent mental capacity advocates where necessary.

At T1, 54 (56.84%) participants were judged as having the capacity to consent

and gave their consent to be included in the research, proxy consent (assent) was

obtained for 13 (13.68%) participants, and best interests meetings were held for the

remainder (28 participants; 29.47%). At T2, 40 (50.00%) participants were judged as

having the capacity to consent and gave their consent to be included in the research,

proxy consent (assent) was obtained for 13 (16.25%) participants, and best interests

meetings were held for the remainder (27 participants; 33.75%). Once consent was

obtained, as previously described, data from the clinical files were collected,

anonymised, and summarised for research purposes.

Demographic information, including gender, age (in years), presence of

autism, and living environment (number of other people lived with), was collected

from participants' files, by the first author, during the data collection process.

Following data collection at T1, the service received a full report of the data

collected (Appendix T), which was distributed to all units within the organisation.

The report in the appendix is a version of the full report received by the service. Due

to confidentiality, it was not possible to include the full report in the appendix. The

full version of the report contained further detail (such as individual unit data etc.).

This report included recommendations on how to improve the physical health of

adults who resided within the residential services. Based on the recommendations

included within the report, the service implemented changes such as employing a

dietician and activity co-coordinators, health promotion for adults with ID and staff

training on the benefits of a healthy lifestyle, in order to improve the BMI of service

users, as well as developing methods to improve relationships with local health care

providers. The first author also used the report as a basis for presentations to staff and

managers within the organisation in order to raise awareness of the data collected and

its implications. Improving physical health of adults with ID within the service was

incorporated into the clinical governance plans, and a clinical governance priority

between T1 and T2. A multi-component weight-loss intervention was designed by the

first author for the residential service. However, due to reasons beyond our control,

the intervention period only last 4 weeks and is therefore only discussed in Chapter 6.

Results

Descriptive analysis of changes in physical health

We first examined longitudinal changes in physical health over the 18-month data collection period, to evaluate the 'action research approach' utilised by the organisation. For these analyses, the symptoms of physical ill- health were coded as a dichotomous (Yes/No) "unhealthy" variable if participants had 16 or more (mean + 1SD) signs and symptoms of physical illness versus fewer than 16. Weight was coded as "unhealthy" if participants were underweight, overweight, obese, or morbidly obese and "healthy" if they were within the recommended range. Physical activity levels were classed as "unhealthy" if participants failed to meet the WHO guidelines for weekly physical activity levels, and "healthy" if they did meet these criteria. Participants who met at least one of the unhealthy categories previously described were defined as being in a globally "unhealthy" sub-group for descriptive purposes. The globally "healthy" group were coded as healthy on each of these three variables.

We coded each health variable in terms of no change (i.e., the same number of total health problems, same BMI category, still meeting the WHO physical activity criteria levels [or not]), worsening problems (more health problems, worsening BMI category, no longer meeting WHO activity guidelines), or improvement (positive change in category). These summary data are displayed in Table 1.

Table 1: Longitudinal improvements, no change or worsening observed in participants' "unhealthy" physical health signs and symptoms, body mass index category (BMI) and physical activity levels.

Physical Health Category	No Change (%)	Improvement (%)	Worsening (%)	TOTAL (%)
Globally Unhealthy/healthy	68 (85.00)	12 (15.00)	0 (0.00)	80 (100.00)
Total symptoms of Ill-health	68 (85.00)	12 (15.00)	0 (0.00)	80 (100.00)
BMI Category	61 (76.25)	13 (16.25)	6 (7.50)	80 (100.00)
Physical Activity Level	44 (55.00)	34 (42.50)	2 (2.50)	80 (100.00)

McNemar's analyses were used to analyse the changes in "unhealthy" categories between T1 and T2, by comparing those who improved category compared to those who worsened or remained in the same category. Twelve participants (15.00%) improved from being globally "unhealthy" at T1 to not having these three indicators at T2. McNemar's test revealed that the proportion of participants who were globally unhealthy at T2 was significantly smaller than the proportion at T1 ($p<.001$).

Twelve participants (15.00%) improved from having an unhealthy number of signs and symptoms of physical ill-health at T1 to having a less unhealthy number at T2, and McNemar's test revealed that the proportion at T2 who were less unhealthy

was statistically significantly lower ($p<.001$). The mean number of health problems

coded as present on the OK Health Check decreased significantly over the 18-month

period from 10.35 ($SD = 6.09$) at T1 to 8.41 ($SD = 4.90$) at T2 (t (79) = -5.03, $p<$

.001, $r = .49$).

Thirteen (16.25%) participants changed from an unhealthy BMI category at

T1 to a healthy BMI category at T2 and McNemar's test showed that these changes

were statistically significant ($p< .001$).

As a whole, participants' physical activity levels were more "healthy" at T2

compared to T1. Only two participants were reported as engaging in lower levels of

physical activity, with the majority of people either remaining in the same category,

while 34 (42.50%) participants improved their physical activity levels between T1

and T2. McNemar's test revealed that the changes between unhealthy levels of

physical activity at T1 and healthy levels of physical activity at T2 were significant

($p<.001$).

Longitudinal analysis of associations between physical and mental health

To examine associations between change in physical health and changes in

mental health and behaviour problems between T1 and T2, we used an ANCOVA

model. Longitudinal changes in physical health (change in 'unhealthy' overall coding,

change in 'unhealthy' signs and symptoms of physical ill health, change in

'unhealthy' BMI categories and change in 'unhealthy' physical activity levels) were

the grouping variables, the relevant Time 1 mental health or behaviour problem score

was entered as a covariate, and the Time 2 mental health or behaviour problem

variable was the dependent variable. Due to the very small numbers of participants

changing category especially worsening over time, it was necessary to group

participants into those who showed improvement in their physical health between T1
and T2 and those who did not improve (i.e. health variables remained the same or
worsened between T1 and T2). These analyses are summarised separately for each of
the mental health and challenging behaviour measures in Tables 2-6.

Table 2: Adjusted means and standard errors for the HoNOS-LD for participants who
improved and who did not improve across physical health categories between Time 1
and Time 2.

	Improved	Did not Improve	*F*	*p*
Change in "Unhealthy" Code	19.711 (2.10)	20.54 (0.95)	$F(1,74) = 0.13$	$p=.722$
Change in "Unhealthy" Signs & Symptoms	19.711 (2.10)	20.54 (0.95)	$F(1,74) = 0.13$	$p=.722$
Change in "unhealthy" weight categories	20.46 (2.21)	20.39 (0.94)	$F(1,74) = 0.001$	$p=.976$
Change in "unhealthy" physical activity levels	21.52 (1.34)	19.60 (1.13)	$F(1,74) = 1.201$	$p=.277$

Table 3: Mean and standard error scores for the presence of SIB for participants who improved and who didn't improve across physical health categories between Time 1 and Time 2.

	Improved	Didn't improve	*F*	*p*
Change in "Unhealthy" Code	0.47 (0.12)	0.36 (0.05)	$F(1,68) = 0.76$	$p=.388$
Change in "Unhealthy" Signs & Symptoms	0.47 (0.12)	0.36 (0.05)	$F(1,68) = 0.76$	$p=.388$
Change in "unhealthy" weight categories	0.48 (0.12)	0.36 (0.05)	$F(1,68) = 0.88$	$p=.352$
Change in "unhealthy" physical activity levels	0.31 (0.08)	0.42 (0.06)	$F(1,68) = 1.36$	$p=.248$

Table 4: Mean and standard error scores for stereotyped behaviours for participants

who improved and who didn't improve across physical health categories between

Time 1 and Time 2.

	Improved	Didn't improve	F	p
Change in "Unhealthy" Code	16.06 (3.29)	11.45 (1.41)	$F(1,72) =1.61$	$p=.209$
Change in "Unhealthy" Signs & Symptoms	16.06 (3.29)	11.45 (1.41)	$F(1,72) =1.61$	$p=.209$
Change in "unhealthy" weight categories	19.98 (3.11)	10.75 (1.36)	**$F(1,72) =7.39$**	**$p=.008$**
Change in "unhealthy" physical activity levels	12.37 (2.10)	12.14 (1.67)	$F(1,72) =0.08$	$p=.931$

Table 5: Mean and standard error scores for aggression for participants who improved and who didn't improve across physical health categories between Time 1 and Time 2.

	Improved	Didn't improve	*F*	*p*
Change in "Unhealthy" Code	29.34 (12.37)	22.87 (5.39)	*F*(1,72) =0.23	*p*=.634
Change in "Unhealthy" Signs & Symptoms	29.34 (12.37)	22.87 (5.39)	*F*(1,72) =0.23	*p*=.634
Change in "unhealthy" weight categories	31.47 (12.33)	22.47 (5.38)	*F*(1,72) =0.45	*p*=.506
Change in "unhealthy" physical activity levels	19.672 (7.96)	26.557 (6.31)	*F*(1,72) =0.46	*p*=.500

Table 6: Mean and standard error scores for the Reiss Screen for participants who improved and who didn't improve across physical health categories between Time 1 and Time 2.

	Improved	Didn't improve	F	p
Change in "Unhealthy" Code	14.98 (2.71)	16.64 (1.23)	$F(1,73) = 0.31$	$p = .578$
Change in "Unhealthy" Signs & Symptoms	14.98 (2.71)	16.64 (1.23)	$F(1,73) = 0.31$	$p = .578$
Change in "unhealthy" weight categories	15.39 (2.71)	16.56 (1.23)	$F(1,73) = 0.15$	$p = .696$
Change in "unhealthy" physical activity levels	16.43 (1.79)	16.30 (1.44)	$F(1,73) = 0.003$	$p = .955$

None of the changes in physical health variables between T1 and T2 were significantly associated with changes in total score on the HoNOS-LD, the presence of SIB, aggression, or the total score on the Reiss screen. Change in BMI, from 'unhealthy' (being underweight, overweight, obese or morbidly obese) to 'healthy' (being of desirable weight) was significantly associated with stereotyped behaviour at T2, $F(1,72) = 7.39$, $p = .008$, $\eta_p^2 = .09$. Participants who improved their BMI between T1 and T2 displayed less stereotyped behaviour at T2, compared to people who did

not improve their BMI (stayed the same or worsened) between T1 and T2, $t(79) = -3.92$, $p<.001$, $\eta_p^2 = .40$.

Discussion

The results showed that between T1 and T2, participants had significantly fewer signs and symptoms of physical health problems, had significantly improved their BMI categories and had significantly improved their physical activity levels. These results indicate that the processes implemented by the residential service following the audit at T1, following an action research model, such as employing a dietician and activity co-coordinators, staff training on the benefits of a healthy lifestyle for adults with ID, improved relationships with local health care providers and health promotion for participants, as well as the awareness raising of the audit data, and incorporating improving physical health into the clinical governance plans, in combination, may have been successful in improving the physical health of adults with ID.

ANCOVA models, to examine associations over time between changes in physical health and changes in mental health and behaviour problems, revealed that improvement in BMI between T1 and T2 was associated with less stereotyped behaviour at T2. None of the other physical health grouping variables entered as covariates at T1 were significant predictors of mental health or challenging behaviour at T2.

In comparison to previous studies, the results reported above are different, as overall, the majority of participants improved their physical health over 18-months. Between T1 and T2 participants were reported as having fewer signs and symptoms of physical ill-health. As stated previously, the majority of the research to date describes worsening of physical health for adults with ID over time (e.g. Ashaye *et*

al., 1998; Cooper *et al.*, 2006; Evenhuis, 1997). However, not only do these studies have different lengths of follow-up periods to this current study (5 years, 1 year and 10 years respectively), but these studies only describe the changes in physical health in adults with ID in terms of the presence of new physical health problems, or the presence of new signs and symptoms, i.e. they do not report the improvement in the physical health of adults with ID. This could be as a result of people's health not improving and therefore there are no data to report, but more likely is that research is focused on the worsening of physical health as opposed to looking for improvements. Improvement data are only typically described in studies that report the result of intervention data. Also, research over the past decades has concentrated on the health inequalities and disparities that people with ID face (for example: Krahn, Hammond & Turner, 2006) and as such little attention has focused on improvements in physical health. Future research needs to look at improvements in the physical health of adults with ID and how these improvements may lead to improvements in mental health and challenging behaviour.

A potential limitation of this study is that the sample consisted of adults with ID from a specialist ID service. Participants were generally placed within the service because of additional needs, such as physical health problems, mental ill-health and challenging behaviours. Therefore, ceiling effects on the standardized measures or for physical health status may have attenuated the associations between physical health and mental health or behaviour problems. Further research with more representative samples is needed.

Another potential limitation for this study is that follow-up data at T2 was conducted 18 months after T1, therefore both time points were at different times of

the year: T1 was in the autumn, while T2 was in the spring. It is therefore possible

that seasonal changes in the weather may have been responsible for changes seen in

levels of physical activity for example. However, previous research has shown little

difference in physical activity levels between autumn and spring. For example,

McCormack, Friedenreich, Shiell, Giles-Corti and Doyle-Baker (2009), assessed

physical activity levels in adults across 4 time-points (once per season) and found that

levels of walking were significantly lower in winter, but no significant differences

were seen between spring, summer and autumn. Higher levels of moderate intensity

physical activity were more likely during the summer months, but no significant

differences were observed in moderate intensity physical activity levels between

spring, autumn and winter. There were no reported significant differences in the

seasonal patterns of vigorous intensity physical activity.

Recommendations for practice

These results have shown the benefits of services using audit data, using an

action research methodology, in order to target areas of clinical governance, which

need to be addressed. Clinical audit is seen as one approach to improving the quality

of health care and in order to prevent ineffective and inefficient practices, attention

must be given to the deficiencies and gaps in the care currently provided (Hopkins,

1996). The introduction of clinical governance into the NHS has resulted in the

improvement and integration of clinical/ care quality along with improvements in

organizations and structures and service performance (Rawlins, 1999). Research

studies suggest that the audit and clinical governance can and does work in many

different countries and healthcare settings (Johnston, Crombie, Davies, Alder &

Millard, 2000). Some of the key facilitators to successful audit include that all staff,

especially management value audit; that the organization fosters a supportive

environment for audit; and that staff have a sense of ownership of the data and the

audit's findings (Johnston *et al.*, 2000).

      Given the considerable inequalities in physical and mental health for adults

with ID, more research attention of the longitudinal changes, as well as the

longitudinal relationship between physical and mental well-being is needed.

Additionally, services should make full use of data available to them and incorporate

at least annual audits of this data into organisational processes to ensure that the

health of adults with ID continues to improve.

Chapter 6. General Discussion.

Adults with intellectual disabilities experience physical health and mental health problems like all other adults. The field of health disparities and inequalities has had much research attention over the past few decades and has resulted in developments in policy and practice. This thesis has expanded upon our existing knowledge of methods to improve the physical health of adults with intellectual disabilities. Three empirical investigations were carried out (Chapters 2, 3 and 5) as well as a systematic review and meta-analysis (Chapter 4). This discussion will summarise the findings from these four chapters and then present the implications of the thesis as a whole, before making recommendations for future research within the field.

Research into improving the physical health of adults with intellectual disabilities who live in residential settings

The purpose of this thesis was to address two broad research questions. The first was to explore the associations between physical and mental health in adults with ID who live in residential settings. Given the considerable numbers of adults with intellectual disabilities who live within residential settings, it is somewhat surprising how little systematic research attention has been given to this area. The second aim of this thesis, was, in collaboration with a local service provider, to design and implement interventions to improve the health of adults with ID who live in residential settings.

To address these two broad research aims, it was first necessary to develop an appropriate method to measure the physical activity levels of adults with ID. Given the wide range of ability levels of adults with ID in these settings, it was decided to design a measure that proxy respondents, for example, support staff, could complete. Chapter 2 describes the process of validating this measure and the results showed that

this measure had very good criterion validity for measuring physical activity levels over a seven-day period when compared to data gathered from an accelerometer during the same period.

This chapter adds to the literature as it is the first study that we know of to design a proxy-respondent physical activity questionnaire for use with adults with ID. It also adds to the literature as it is the first measure of its kind to ask people to record physical activity levels at the end of a segment of each day (e.g. morning, afternoon, or evening), rather than recalling physical activity levels up to a week later.

Chapter 3 begins the work of describing the physical health, mental health and challenging behaviour of adults with ID who live in residential settings, using descriptive data. Chapter 3 also describes the associations between physical health, mental health and challenging behaviour using correlational and regression methods. The data revealed relatively poor physical health in terms of the number of residents who were overweight, obese or morbidly obese, who did not participate in adequate levels of physical activity, and in terms of the numbers of adults with ID who displayed the signs and symptoms of physical ill-health. Physical health variables accounted for some of the additional variance in mental health problems, depression and problem behaviours.

Very few associations between physical health, mental health and challenging behaviours were observed in this sample, despite the links between these being reported in the ID (e.g. Smiley *et al.*, 2007) and non-ID literature (Moussavi *et al.*, 2007). Despite this, our study has added to the literature in that this was the first study that we are aware of to look for the associations between physical health, mental health and challenging behaviour in adults with ID who live within residential

services. This study also adds to the literature as it is the first study to utilise physical

health data extracted from a health checklist to address these research questions.

Chapter 4 of this thesis describes the results of a systematic review and meta-

analysis summarising the evidence for multi-component weight-loss interventions for

adults with ID. Despite these types of interventions being carried out for several

decades (e.g. Fisher, 1986) and these types of interventions being the treatment of

choice for adults who are overweight or obese (e.g. NICE, 2006) only eight studies

met inclusion criteria for this review. All of the eight studies reported that adults with

ID lost weight between pre- and post-intervention. However, when all of the studies

were combined, the pre- to post-intervention meta-analytic mean difference effect size

for changes in BMI and weight were not statistically significant and were also small

in terms of clinical meaning.

Despite these disappointing results, this review and meta-analysis chapter adds

to the literature as it is the first systematic review with meta-analysis to evaluate the

effectiveness of multi-component weight-loss interventions for adults with ID. We

also addressed the main limitations of two other reviews in this field by: 1.

Conducting a systematic review without date limits to identify all of the previous

literature, and 2. Combining and conducting a meta-analysis of the available data.

The final empirical study addressed changes in the physical health of

participants as a result of the collaborating service designing and implementing

interventions to improve the health of adults with ID within the service. Chapter 5

also looks investigates if improving physical health improves participants' mental

health and challenging behaviours over the same 18-month period. The data described

in this chapter were the follow-up data of the first survey in Chapter 3. The results

showed that between T1 and T2 the majority of participants improved in terms of

their physical health. Improvements in some aspects of physical health were also associated with some improvements in mental health and challenging behaviour. However, these associations were once again small in number.

This chapter adds to the previous literature as it reports improvements in the physical health in adults with ID over 18-months, as a result of the service utilising an "action research' approach. This study shows that services that provide care for adults with ID can use an action research model to make use of the vast quantities of data that these services collect, in order to target specific areas of care, in order to improve the physical health of their service users.

Strengths and limitations of the current research

Whilst this thesis makes a unique contribution to the field of research about the physical health of adults with ID who live in residential settings, it is not without its limitations. These limitations, along with the strengths of the research, are discussed below.

The first limitation is the potential sampling bias, which may have occurred in Chapters 2, 3 and 5. For example, in Chapter 2, it is possible that participants, who chose to take part in the study for the validation of the proxy respondent physical activity questionnaire, were more physically active. This may have been the reason why the results were different to those previously reported in other validation studies for physical activity questionnaires in adults with ID (e.g. Melville *et al.*, 2012).

In Chapters 3 and 5, sampling bias may have occurred as a result of recruiting participants from specialist residential services. Adults with ID are typically placed within these types of services as a result of having additional needs, such as physical health problems, mental health problems or challenging behaviours that could not be

adequately supported and managed in the community. It is, therefore, not surprising that most of the participants described in Chapters 3 and 5 had high levels of physical health problems, mental health problems and challenging behaviours. This may have been the reason why we were not able to detect associations between these three domains of health.

The specialist nature of this service setting for recruitment of participants may also be viewed as a strength of this research. Very little research has described the unique and specialist needs of adults with ID who live in modern residential services. As such, Chapters 3 and 5 go some way to contributing to the knowledge base in this field.

Another potential limitation for the studies contained in this thesis is the small numbers of participants contained within studies. This is especially true for the research in Chapter 2, which validated a new method for measuring physical activity in adults with ID. Only 16 participants were included in the study. However, similar numbers of participants have been used in previous research which has validated physical activity questionnaires (e.g. Momenan *et al.*, 2012) and data collection was intensive and thus difficult to manage within the limited resources of PhD research.

Very few studies were available for inclusion into the meta-analysis into the effectiveness of multi-component interventions for weight-loss in adults with ID. As a result of the very small numbers of studies available for inclusion in the meta-analysis, it was not possible for us to assess the effect of moderator variables (such as the type of components, who delivered the intervention, the length of the intervention) when analysing the overall effectiveness of these types of interventions for adults with ID who were overweight or obese. As mentioned previously in Chapter 4, the

quality of the evidence, which was included in the meta-analysis, was poor (i.e. not

Type-I studies – of the highest methodological rigor; Nathan & Gorman, 2002).

The methods used in Chapter 3 to assess the associations between physical

health problems, mental health problems and challenging behaviours were cross-

sectional in nature, and this may be viewed as a methodological weakness.

Longitudinal methods are necessary when establishing possible causality and

temporal precedence between the variables under investigation. As well as co-

variation and non-spuriousness of the variables, temporal precedence must be

established to demonstrate causality (Haynes, 1992).

The follow-up data collection period was for a period of 18 months and this

may be considered to be a short period. However, Cooper *et al.* (2006) had a follow-

up period of 1 year, while Ashaye *et al.* (1998) and Evenhuis (1997) had longer

follow-up periods (5 and 10 years respectively). The research we have therefore

presented, is similar to the Cooper *et al.* research in utilising a relatively short period

of time between data collection.

As this study was longitudinal in nature, another potential limitation of this

study is that T1 was in the autumn and T2 was in the spring, therefore seasonal

variations may have been responsible for the changes seen in variables such as

physical activity levels. However, previous research in adults without ID has

suggested that physical activity levels do not vary substantially between spring and

autumn. For example, McCormack, Friedenreich, Shiell, Giles-Corti and Doyle-Baker

(2009) assessed physical activity levels in adults across 4 time-points (once per

season) and found that levels of walking were significantly less likely in winter, but

no significant differences were seen between spring, summer and autumn. Levels of

moderate intensity physical activity were more likely during the summer months, but

no significant differences were observed in moderate intensity physical activity levels between spring, autumn and winter. There were no reported significant differences in the seasonal patterns of vigorous intensity physical activity.

Theoretical Implications

Adults with intellectual disabilities (ID) experience worse health outcomes compared to adults without ID. There are numerous, often multifactorial, reasons for this, including genetic and biological factors related to the cause of ID, but also wider social determinants of health, such as education, housing, deprivation, and lower levels of health literacy or poor service outcomes. Risk factors for mental ill-health in adults with ID follow a bio-psycho-social continuum, with genetic abnormalities, abnormal brain structures, stigmatization, lack of adaptive behaviours, lack of social contact and poor education being important contributors (Azam *et al.*, 2010).

Clinical health psychology relates psychological variables to biomedical conditions to understand health outcomes and their effects on quality of life and *vice versa*. The biopsychosocial model of ill-health states that ill-health is the "product of a combination of factors including biological characteristics (e.g. genetic predisposition), behavioural factors (e.g. lifestyle, stress and health beliefs), and social conditions (e.g. cultural influences, family relationships, social support)" (APA, 2005). As such future researchers within this field need to take all of these three aspects into account when designing new interventions to improve the physical health of adults with ID who live in residential services.

As described throughout this thesis, adults with ID who live within residential settings are very dependent on others for all aspects of their daily lives. As such, it is vitally important that interventions that aim to improve their physical health and

ultimately their quality of life, take into account their unique needs. Not only should

adults with ID take an active part in these interventions, but the staff who support

them should also be actively involved. Social cognitive theory (SCT) explains

behaviour in terms of a triadic, dynamic, and reciprocal model in which behaviour,

personal factors, and environmental influences all interact (McAlister, Perry & Parcel,

2004). According to this theory, health behaviours can be improved through both

personal factors (knowledge, skills, preferences, self-efficacy) of residents as well as

through improvements in their social and physical environment, which is very much

dependent on knowledge, skills and work routines of the staff. This theory may

therefore be best placed to explain why adults with ID who live in residential services

may experience poor physical health. This theory may also be best placed to inform

future interventions, which aim to improve the physical health of adults with ID who

live in residential services.

Practical implications

        The findings of the studies included within this present thesis have

implications for the design of interventions for adults with ID. In chapter 2, we

described the benefits of physical activity for adults with ID. The measure that we

have designed to measure the physical activity levels of adults with ID was shown to

be valid. Services within the community (for example day services) as well as more

specialist services (for example residential services) could use the IPAQ-pr to

measure the physical activity levels of adults with ID, to ensure that service users are

engaging in adequate levels of physical activity every week. Services, both

specialised residential, and those which are community-based, need to ensure that

physical activities are offered as choices when designing activity programmes, in

order to ensure that adults with ID benefit from the health-promoting effects of adequate physical activity levels.

Chapter 5 showed the benefits of using data and an action research model within services to target areas of clinical governance, which need to be addressed. This approach, of making services aware of changes that need to be made service-wide, will benefit more adults with ID, rather than a few, if an individualised approach were to be taken.

Given the numbers of adults with ID who were classed as overweight, obese or morbidly obese in Chapter 3, it is clear that policies and initiatives within day- and residential services, do not typically prevent adults with ID from living healthy lifestyles. Following on from the recommendation above, policies should ensure that adults with ID are offered healthy choices in terms of their diet and in terms of the activities that are offered. Nationally, health education campaigns need to ensure that they are accessible to adults with ID as well as other disadvantaged groups within society.

The systematic review and meta-analysis (Chapter 3) also highlighted the need for well designed multi-component weight loss interventions that are specifically designed for adults with ID. As a result of this systematic review and meta-analysis as well as the results that were presented (Chapter 2) to the residential service, it was decided that we should design, and assess, a multi-component weight-loss programme for adults with ID. The "Healthy Lifestyle Project" was a multi-component weight-loss programme, which included health education sessions, personalised dietary prescriptions, and increased physical activity levels (Appendix S).

Those in the HLP group had their diet assessed by a qualified dietician and an individualised dietary prescription was provided for them. The intervention group

were to receive weekly educational sessions as a group and their weekly data recorded on the data collection form. The fidelity of these weekly sessions was to be assessed using the fidelity assessment form, which was to be completed by the principle investigator. If the principle investigator was unable to attend the sessions, the sessions were recorded for the investigator to complete the form at a later date.

In addition to the weekly group sessions, participants were encouraged to increase their physical activity levels by attending physical activity sessions and classes within the local community. Lists of these local classes/sessions were provided to the activities co-ordinator in each of the residential units. In addition, "taster-sessions" were organised for the HLP group, as many of the participants had not had the opportunity to take part in different sports and exercise classes in the past, thus giving participants the opportunity to discover activities that they would enjoy. It was hoped that by doing this, participants would be more likely to want to take part in physical activity. The intention was to encourage participants to reduce the time that they engaged in sedentary behaviour (e.g. sitting using a computer, or watching T.V.).

The health education and behaviour modification components of the HLP were based on *Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities* (Marks, Sisirak & Heller, 2010) and were adapted where necessary to make concepts easier to understand using more relevant examples.

Post-intervention data were to be collected for both the HLP and waiting list control groups. Following the intervention component, a maintenance phase was to be introduced, where the intervention group received monthly group sessions, based on the same curriculum. However the emphasis was to be on maintaining a healthy weight. Participants would also be encouraged to continue engaging in physical

activity. 3-, 6- and 12-month follow up data were to be collected for both the HLP and waiting list control groups.

Unfortunately, the residential service provider had to withdraw the intervention after only a few sessions due to reasons beyond our control. It is for this reason that it was not possible to evaluate the effectiveness of this multi-component weight loss intervention for adults with ID in this thesis. More research is now needed to evaluate the effectiveness of this programme in order to provide an evidence base from which clinicians can work.

Recommendations for future research

Though this thesis has contributed significantly to the research area of the physical health of adults with ID who live in residential settings, there remain many unanswered questions. I will now discuss the outstanding issues and suggest how future research may address these issues.

In terms of validation of the proxy respondent physical activity questionnaire, further research is needed in order to validate this measure in a larger sample. A larger sample would also be more likely to contain participants who had varying physical activity levels, as the participants recruited for the validation study in Chapter 2 were mostly very active. All of the participants who took part in the validation study in Chapter 2 also had the capacity to consent and therefore we can assume that all of the participants had mild to moderate deficits in their intellectual functioning. Future research is needed to validate the IPAQ-pr with a broader range of levels of intellectual functioning. Although the IPAQ-pr was designed to measure the physical activity levels of adults with ID, there is no reason why the measure cannot be used to measure the physical activity levels of children (with or without ID).

Alternatively, the format of the IPAQ-pr could be utilised as a new format for measuring physical activity in adults with mild to moderate ID, as a self-report measure. Future research is therefore needed to design a version of the IPAQ-pr that would be suitable for adults with ID to complete as a self-report measure, and to validate this measure compared to a proxy respondent physical activity questionnaire as well as accelerometer data.

To assess the associations between physical health, mental health and challenging behaviour in adults with ID, future research needs to be of a larger scale; more methodologically sound and longitudinal in nature in order to establish the patterns of these associations in adults with ID. This research needs to be conducted with adults with ID who not only live in residential service settings, but with those who reside in the community in order to make results generalisable to the whole population of adults with ID. Interventions which propose to improve the physical health of adults with ID, should consider assessing mental health variables pre- and post-intervention, in order to evaluate these potential associations. Similarly, interventions, which aim to improve some aspect of mental health or to reduce challenging behaviours, could also consider including a measure to assess general physical health, again, to research the associations between these variables.

Further research attention needs to be given to the potential of using the results from data collected from within organisations and services to improve clinical outcomes for all services users. By reporting the findings of the research described in Chapter 2 to senior management, clinical staff and managers of individual residential units, especially when comparing data on a unit-by-unit basis, informally, staff reported this as being informative and useful, and wanted to improve to be on a par with, or better than, other residential units. Within ID community- and residential-

based services, masses of data are collected and stored with service users' files. By bringing these data together and analysing them, patterns of need will become apparent.

Future research focused on the evaluation of the effectiveness of multi-component weight-loss interventions for adults with ID needs to be of a higher quality. Specifically, control groups are needed, where participants are matched on the basis of important characteristics, such as gender, ability level and starting body weight, and participants should be randomly allocated to intervention or control groups. Research needs to ensure that these participants are followed-up for at least 6-months after the end of the intervention period in order to ascertain whether weight-loss as a result of the intervention are maintained in the long term. Researchers also need to assess the quality, such as the fidelity, of the sessions. Future research also needs to focus on the feasibility of running these types of interventions within different settings and in different services, to make sure that the potential benefits from these interventions are generalizable to all adults with ID.

Conclusions

The physical health needs, mental health needs and challenging behaviours (and how these interact) of adults with ID who live in residential services are complex and vast. Therefore, research needs to focus on a variety of factors when attempting to improve the physical health of adults with ID. This thesis has employed different research strategies to look at methods of improving the physical health of adults with ID who live in residential services, and shown how these improvements in physical health may have a positive impact on their mental health and levels of challenging behaviour. This thesis has also recommended future applied research that is now

needed, as well as the practical implications of the research, in order to improve the

health of adults with ID who live in residential settings.

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Appendix A
IPAQ-pr

IPAQ –Proxy Respondent Version

INSTRUCTIONS

1.Label the worksheet with the appropriate date (when recording began), participant's name, date of birth etc.

2. Record time that the participant woke up and went to bed.

3. Time segments should be recorded in l5-min time blocks (for example ¼ hour, ½ hour, ¾ hour, 1 hour, 1 ¼ hour etc) for time spent asleep and doing the activities mentioned below

4. Record time spent sleeping & sitting still in spaces provided on worksheet (i.e. once awake – naps etc).

5. Record time spent walking (both as an activity and walking around the house/ward etc).

6. Record time spent doing activities in spaces provided on worksheet for morning, afternoon, and evening at the various levels of intensity. Also list the different activities done. See information sheet for examples of different activities in each of the intensities. Only list activities if the person did those activities for more than 10 minutes at a time.

7. If you are not sure if an activity is classed as moderate, hard or vigorous physical activity, or it was an activity not on the list, please write this on the back of the sheet. Indicate what the activity was, on what day it was completed and the time spent doing that activity.

9. Please also fill in your own details on the table – your initials and job title, as well as the shift that you worked. This will allow us to get in touch with you if we have any questions about the form.

Appendices

Moderate Activities
These activities involve modest increases in heart rate & breathing—e.g., many household & home repair tasks.

☐ Calisthenics without weights (lunges, jumping jacks, sit ups, crunches, push ups etc)
☐ Carpentry
☐ Cleaning, heavy (such as vacuuming, sweeping)
☐ Croquet
☐ Cycling—leisure, 5.5 mph mild
☐ Electrical work
☐ Feeding farm animals, manual milking
☐ Fencing
☐ Forestry—slow axe chopping, power sawing, stacking firewood, weeding
☐ Frisbee playing
☐ Gardening—hedging, raking, planting, mowing
☐ Golf—no power cart
☐ Gymnastics
☐ Horseback riding
☐ Locksmith
☐ Machine tooling—lath, punch press, tapping & drilling, welding
☐ Mopping floor
☐ Motor-cross
☐ Mowing lawn—push & power mower
☐ Music—playing drums
☐ Painting—outside
☐ Planting seedlings
☐ Plastering
☐ Sailing & board sailing
☐ Scraping Paint
☐ Surfing
☐ Sweeping
☐ Swimming—mild
☐ Grocery shopping
☐ Table tennis
☐ Laundry—heavy
☐ Childcare
☐ Window cleaning
☐ Walking on firm level surface, 3-4 mph – Average to fairly brisk
☐ Yoga
☐ Tai-chi
☐ Bowling
☐ Grocery shopping
☐ Heavy cooking

Hard Activities   142
Most people will have noticeable increases in breathing and will likely perspire—e.g., vigorous household, home repair and gardening tasks, heavy industrial work, and some construction and vigorous sports.

☐ Aerobic Dance
☐ Badminton
☐ Climbing hills with no load
☐ Coal shovelling
☐ Cycling—leisure, 9.4 mph (moderate)
☐ Farming—shovelling grain
☐ Fast Walking
☐ Folk Dancing
☐ Forestry—hoeing, planting by hand
☐ Karate or Judo
☐ Roller skating
☐ Scrubbing floors
☐ Skiing, water or downhill
☐ Tennis, doubles
☐ Walking on level Brisk or striding, firm surface @ 4.5 mph
☐ Weight lifting or training (count only lifting time)
☐ Swimming—moderate

Vigorous Activities
These include strenuous sports involving a lot of movement and running. Very few household or occupational tasks are included, except carrying heavy loads, digging or chopping with heavy tools, or other similar hard physical labour.

☐ Boxing—in ring, sparring
☐ Circuit training
☐ Climbing hills with 5-20 kg load
☐ Cycling, racing (intensive)
☐ Digging ditches
☐ Farming—barn cleaning
☐ Field hockey
☐ Football
☐ Forestry—fast axe chopping, barking trees, carrying logs, sawing by hand
☐ Gardening, digging
☐ Marching, rapid
☐ Racquetball (Squash)
☐ Rope jumping
☐ Running, jogging—cross country, 6-10 min/mile

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

MONDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

TUESDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

WEDNESDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

THURSDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

FRIDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	**AFTERNOON (12noon-6pm):**	**EVENING 6pm-Bed Time**
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

SATURDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Proxy Respondent Version of the IPAQ

Participant's Name   Participant's DoB

Week beginning

SUNDAY TIME SPENT SLEEPING & DOING EXERCISE & EXAMPLES OF THE EXERCISES DONE BY PARTICIPANT

	MORNING TIME AWAKE-12noon	AFTERNOON (12noon-6pm):	EVENING 6pm-Bed Time
Time Awake			
Sitting/Sleeping			
Walking			
Moderate Physical Activity			
Hard Physical Activity			
Vigorous Physical Activity			
Time to bed			
Completed by (initials) & position			
Shift worked			

Appendix B
IPAQ-pr: Information Sheet- Participants with Intellectual Disabilities

Participant Information Sheet

What we would like to know?

We would like to find out about and how much physical activity you do in a week and what types of physical activity you do.

We also want to find out how people fill in physical activity forms.

What will happen?

1) We will ask you for your permission.

2) If you agree, we will ask you to wear an accelerometer for seven days. An accelerometer is a small machine that you wear on your leg. This is used to measure how much physical activity, such as walking, running or cycling, you do every day. It also measures how hard your body works when you do these activities.

3) At the same time, we will ask people who know you well to fill in a form about how much physical activity you do.

4) We will put this information onto a computer, but we won't use your name, your age or where you live.

5) If you agree to us looking at your information, we will look to see how much physical activity lots of other people do. We will also look to see how people fill in physical activity forms.

6) We will use this information to help us understand more about physical activity in adults with intellectual disability.

Can I say no?

- It's ok if you want to say no

- You can say no now or later, if you change your mind

- You can tell us or a member of staff at any time if you don't want to do this

Questions

- You can ask anything you would like to now

- Or you can ask any member of staff to phone us and ask a question for you.

Taflen Wybodaeth i Gyfranogwyr

Beth yr hoffem ei wybod?

Hoffem wybod faint o weithgaredd corfforol yr ydych yn ei wneud mewn wythnos, a pha fathau o weithgareddau corfforol y byddwch yn eu gwneud.

Rydym hefyd yn awyddus i ganfod faint o bobl sy'n llenwi ffurflenni am eu gweithgareddau corfforol.

Beth fydd yn digwydd?

1) Byddwn yn gofyn am eich caniatâd.

2) Os cytunwch, byddwn yn gofyn ichi wisgo mesurydd ymarfer corff am 7 diwrnod. Mae mesurydd ymarfer corff yn beiriant bach yr ydych yn ei wisgo ar eich coes. Defnyddir hwn i fesur faint o weithgaredd corfforol, megis cerdded, rhedeg neu seiclo a wnewch bob dydd. Mae'n hefyd yn mesur pa mor galed y mae eich corff yn gweithio pan fyddwch yn cyflawni'r gweithgareddau hyn.

3) Ar yr un pryd, byddwn yn gofyn i bobl sy'n eich adnabod yn dda lenwi ffurflen ynglŷn â faint o weithgaredd corfforol yr ydych yn ei wneud.

4) Byddwn yn rhoi y wybodaeth yma ar gyfrifiadur, ond ni fyddwn yn defnyddio eich enw, eich oedran na lle rydych yn byw.

5) Os caniatewch inni edrych ar eich gwybodaeth, byddwn yn edrych i weld faint o weithgaredd corfforol y mae llawer o bobl eraill yn ei wneud. Byddwn hefyd yn ceisio gweld sut y mae pobl yn llenwi ffurflenni am weithgareddau corfforol.

6) Byddwn yn defnyddio'r wybodaeth hon i'n helpu i ddeall mwy am weithgaredd corfforol ymysg oedolion ag anableddau deallusol.

A gaf ddweud 'Na'?

- Mae'n iawn dweud 'Na'.
- Gellwch ddweud 'Na' yn awr neu'n ddiweddarach, os byddwch yn ail-feddwl.
- Gellwch ddweud wrthym ni neu wrth aelod o'r staff/ eich teulu ar unrhyw adeg os nad ydych am wneud hyn.

Cwestiynau

- Gellwch ofyn unrhyw gwestiwn yn awr.
- Fel arall, cewch ofyn i unrhyw aelod o'r staff/ aelod o'ch teulu ein ffonio a gofyn cwestiwn ar eich rhan.

Appendix C
IPAQ-pr: Information Sheet-Family Members and Staff

Staff/Family Member Information Sheets

The validity and reliability of the proxy-respondent International Physical Activity Questionnaire (IPAQ) to measure physical activity in adults with intellectual disabilities (ID).

Information about the study
You are invited to take part in a research study to assess the levels of physical activity/exercise in adults with intellectual disabilities (ID) and to see what types of physical activity people with ID do over a one-week period. We are also interested in how well the proxy respondent version of the International Physical Activity Questionnaire (IPAQ-pr) works as a tool for measuring physical activity in adults with ID.

Why have I been asked to take part?
You have been asked to take part because you are the carer for someone with an ID who has indicated that they would like to take part in the study. As you support their daily activities, you are one of the people who will most likely know a lot about the type of exercise this person takes part in and how often they exercise.

What does the study involve?
The study will require you to complete a questionnaire every day over a one-week period. You will be asked to do this at the same time as the adult with ID wears the accelerometer. This questionnaire should take no longer than 10 minutes to complete every day, and is simple to fill in.

Are there any benefits or risks?
We do not anticipate that there will be any risk to you from filling out the questionnaires. Whilst there will be no direct benefits to you, the study will help us to get a better picture of the exercise patterns of people with ID. We will also be able to see whether carers can accurately tell how much exercise their family member/client with ID takes part in. This will be very useful information to have as from it we may be able to develop ways to make sure that enough exercise takes place each day.

What will happen to my data?
All data collected will be confidential, and you will not be identifiable in any report, thesis or publication which arises from this study. The data from this study will be stored securely for 5 years. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don't want to take part?

It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact any other aspect of your relationship with Bangor University.

Who do I contact about the study?
If at any time you wish to talk with someone about the study, or to make a comment,
ask a question etc., please contact Ms Ceri Christian-Jones on this address.
Ms Ceri Christian-Jones
School of Psychology
Bangor University
Bangor
Gwynedd
LL57 2AS
(phone 01248 388656 during office hours or email ceri.christian-jones@bangor.ac.uk)

Who do I contact with any concerns about this study?
If you have any concerns or complaints about this study, or the conduct of individuals
conducting this study, then please contact Mr Hefin Francis, School Manager, School
of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS or e-mail
h.francis@bangor.ac.uk

Taflenni Gwybodaeth ar gyfer Staff/ Aelodau'r Teulu

Pa mor ddilys a dibynadwy yw'r Holiadur Rhyngwladol ar Weithgaredd Corfforol (IPAQ) i fesur gweithgaredd corfforol yn achos oedolion ag anableddau deallusol (AD).

Gwybodaeth am yr astudiaeth
Mae gwahoddiad ichi gymryd rhan mewn astudiaeth ymchwil i asesu lefelau gweithgaredd corfforol/ ymarfer corff yn achos oedolion ag anableddau deallusol (AD), ac i ganfod pa fathau o weithgareddau corfforol y mae pobl ag AD yn eu gwneud dros gyfnod o wythnos. Mae gennym hefyd ddiddordeb yn y modd y mae fersiwn y dirprwy ymatebydd ar gyfer yr Holiadur Rhyngwladol ar Weithgaredd Corfforol (IPAQ-pr) yn gweithio fel offeryn ar gyfer mesur gweithgaredd corfforol ymysg oedolion ag Anableddau Deallusol.

Pam y gofynnwyd imi gymryd rhan?
Gofynnwyd ichi gymryd rhan am eich bod yn gofalu am rywun ag anabledd dysgu sydd wedi dangos yr hoffai gymryd rhan yn yr astudiaeth. Gan eich bod yn ei g/chynorthwyo yn ei (g)weithgareddau beunyddiol, rydych yn un o'r bobl a fydd fwyaf tebygol o wybod am y math o ymarfer y mae'r unigolyn hwn yn gymryd rhan ynddo a pha mor aml y bydd ef/hi'n ymarfer.

Beth y mae'r astudiaeth yn ei olygu?
Bydd yr astudiaeth yn gofyn ichi lenwi holiadur bob dydd yn ystod cyfnod o wythnos. Gofynnir ichi wneud hyn ar yr un pryd ag y mae'r oedolyn ag Anabledd Deallusol yn gwisgo'r mesurydd ymarfer corff. Ni ddylai'r holiadur gymryd mwy na 10 munud i'w lenwi bob dydd, ac mae'n syml

A oes unrhyw fuddion neu risgiau?
Nid ydym yn rhagweld y bydd unrhyw risg i chi o lenwi'r holiaduron. Er na fydd unrhyw fuddion uniongyrchol i chi, bydd yr astudiaeth yn gymorth mawr i ni gael gwell syniad am batrymau ymarfer pobl sydd ag anableddau dysgu. Byddwn hefyd yn gallu gweld a all cynhalwyr nodi'n gywir faint o ymarfer corff y mae eu perthynas/ cleient ag AD yn cymryd rhan ynddo. Bydd hyn yn wybodaeth fuddiol iawn, am y gall fod yn sail inni ddatblygu ffyrdd o sicrhau bod digon o ymarfer yn digwydd bob dydd.

Beth fydd yn digwydd i'm data?
Bydd unrhyw ddata a gesglir yn gyfrinachol, ac ni fydd modd eich adnabod mewn unrhyw adroddiad, thesis na chyhoeddiad a fo'n deillio o'r astudiaeth hon. Cedwir y data o'r astudiaeth hon yn ddiogel am 5 mlynedd. Os penderfynwch roi'r gorau i'r astudiaeth, a bod modd i'r tîm ymchwil adnabod eich data, mae gennych hawl i ofyn am beidio â defnyddio eich data.

Beth fydd yn digwydd os nad wyf am gymryd rhan?

Mater i chi yw penderfynu p'un a hoffech gymryd rhan yn yr astudiaeth hon neu beidio. Os penderfynwch beidio â chymryd rhan, ni chaiff hynny unrhyw effaith ar eich cysylltiad â Phrifysgol Bangor.

Â phwy y cysylltaf ynglŷn â'r astudiaeth?
Os hoffech ar unrhyw adeg drafod yr astudiaeth â rhywun, neu gyflwyno sylw, gofyn
cwestiwn ayyb, cysylltwch â Ms Ceri Christian-Jones yn y cyfeiriad hwn.
Ms Ceri Christian-Jones
Ysgol Seicoleg
Prifysgol Bangor
Bangor
Gwynedd
LL57 2AS
(☎01248 388656 yn ystod oriau swyddfa, neu e-bost ceri.christian-
jones@bangor.ac.uk)

**Â phwy y dylwn gysylltu os bydd gennyf unrhyw bryderon ynglŷn â'r astudiaeth
hon?**
Os oes gennych unrhyw bryderon neu gŵynion ynglŷn â'r astudiaeth hon, neu ynglŷn
ag ymddygiad unigolion sy'n cynnal yr astudiaeth hon, cysylltwch â Mr Hefin
Francis, Rheolwr, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd LL57 2AS,
neu anfonwch e-bost at h.francis@bangor.ac.uk .

Appendix D
IPAQ-pr: Functional Assessment of Capacity

Mental Capacity Act 2005
Functional Assessment of Capacity
CONFIDENTIAL

Name……………………………...……………………………………………..

DIAGNOSTIC THRESHOLD
Does the patient/resident have an impairment of, or a disturbance in, the functioning of the mind or brain?   **YES**   **NO**

If **YES** record nature of the disturbance

Neurological DisorderIntellectual disability Mental Disorder
Dementia   Stroke   Head Injury
Delirium   Unconsciousness   Substance Use
Other (give details)

NATURE OF DECISIONS/ACTIONS/INTERVENTIONS PROPOSED
Record below the nature of the decision for the person being assessed

FUNCTIONAL ASSESSMENT
1. Is the patient/resident able to understand the relevant information, for example, the purpose of the research and the consequences of using data for research purposes?
                                                        YES   **NO**
Give details

2. Is the patient/resident able to retain the relevant information (as above)?
                                                        YES   **NO**
Give details

3. Is the patient/resident able to use or weigh the relevant information as part of the decision making process (as above)?
                                                        YES   **NO**
Give details

4. Is the patient/resident able to communicate the decision(s) verbally or non-verbally (as appropriate)?

YES   **NO**

Give details

Answering no to 1-3 indicates lack of capacity – complete "Best Interests Checklist" and refer decision to "Best Interests Meeting".
Answering no to 4 DOES NOT indicate incapacity – ensure practical measures are used to enable communication, for example liaising with Speech & Language Therapist.

Details of Assessor

Name…………………………………………………………………………

Nature of professional relationship……………………..………………………

Nature of interest (financial or other) in matter for which assessment was carried out

……………………………………………………………………………………

……………………………………………………………………………………

Signed…………………………………………………………………………….

Date & Time…………….……………………………………………………….

Details of Witness

Name……………………….………………………………………...………..

Nature of professional relationship……………..…………………………………

Signed……………………………….…..………………………………………..

Date & Time…………………………………………………………………………

Guidelines for the Functional Assessment of Capacity

Diagnostic Threshold

The Mental Capacity Act (2005) acknowledges that if there is an established diagnosis of mental illness, intellectual disability or some other condition, then this is sufficient to confirm "impairment or disturbance of the mind".

Nature of decision

Assessors should record the key decisions facing participants/patients

Test

1. **Understanding the information**

    The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process

2. **Retaining the information**

    Information only needs to be held in the mind of the person long enough to make the decision.

3. **Use or weigh the information**

    Some people can understand the information, but an impairment stops them from using it. Whereas others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could foresee the consequences of making, or failing to make, that decision.

4. **Communicate the decision**

    Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc).

Protocol for Assessing Capacity

1. Read the information sheet once to the participant

2. Read the following part of the information sheet: **"We would like to find out about and how much physical activity you do in a week and what types of physical activity you do. We also want to find out how people fill in physical activity forms."**

   Ask the participant "**What do we want to find out?"**

   Score 1 if the person gives an answer similar to **"To find out about my physical activity and how people fill in forms"**
   Score 0 if the answer is irrelevant or too vague

3. Read the following part of the information sheet. **"If you agree, we will look to see how much physical activity lots of other people do. We will also look to see how well people fill in physical activity forms. We will use this information to help us understand more about physical activity"**

   Ask the participant **"Why do we want to do this?"**

   Score 1 if the person gives an answer similar to **"To see how much physical activity other people do and see how people fill in form. To help understand more about physical activity"**
   Score 0 if the answer is irrelevant or too vague

4. Read the following part of the information sheet.

   Ask the participant **"Are you happy for me to come to collect this information?"**

   Answer Yes or No.

   Ask the participant **"Are you happy for me to share the information to help other people with a learning disability?"**

   Answer Yes or No.

   For consent to be given the participant needs to answer Yes to both questions.

5. Read the following part of the information sheet: **"If you say yes, but then you change your mind that's OK. It's OK to say no if you want to. You can say no now, or if you change your mind later. You can tell us, or a member of staff at any time."**

Ask the participant: **"What will you do if you change your mind?".**

Score 1 for any similar to "Tell you No"
Score 0 if answer is irrelevant or too vague.

Overall Scoring
If the participant scores 0 to any of the questions under items 2,3 or 5, then the participant is assessed as not having the capacity to consent in this specific context. If the participant does not have the capacity to participate then the researchers should not use this participant in the research.
If the participant scores 1 in every question under items 2,3,4, and 6 and answer "Yes" to both questions under item 4, the participant is assessed as having the capacity to consent and he/she is indicating their wish to participate in this research.
If the participant scores 1 in every question under items 2,3, and 6 but answers "No" in question 4, the participant is assessed as having the capacity to consent but is indicating his/her refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D,. & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities,* 11(1), 77-83.

Appendix E
IPAQ-pr: Consent form- Participants with Intellectual Disabilities

CONSENT

1. I have been given information about the study

   YES   NO

2. I have been able to ask questions if I wanted

   YES   NO

3. I know that I can say no at any time

   YES   NO

4. I am happy for my information to be used

   YES   NO

Written Consent

Signed…………………………………………………………………

Date……………………………………………………………………

Verbal Consent
                 YES   NO   N/A

Witnessed by …………………………………………………………………..

Name……………………………………………………………………………

Position…………………………………………………………………………

Date & Time……………………………………………………………………

Researcher…………………………Name…………………………………………

Date & Time……………………………………………………..………………

CYDSYNIAD

5. Rwyf wedi cael gwybodaeth am yr astudiaeth

   YDWYF   NAC YDWYF

6. Rwyf wedi cael cyfle i ofyn cwestiynau os oeddwn yn dymuno

   YDWYF   NAC YDWYF

7. Rwy'n gwybod y gallaf ddweud 'Na' ar unrhyw adeg

   YDWYF   NAC YDWYF

8. Rwyf yn fodlon i wybodaeth amdanaf gael ei defnyddio

   YDWYF   NAC YDWYF

Cydsyniad Ysgrifenedig

Llofnod: …………………………………………………………

Dyddiad …………………………………………………………

Cydsyniad Llafar
                    ✓   ✗   **AMHERTHNASOL**

Tystiwyd gan …………..……………………………………………………………

Enw ……………………………………………………………………..

Swydd ……………………………………………………………………..

Dyddiad ac Amser ..………………………………………………………....

Ymchwilydd …………………………….Enw …………………………………………

Dyddiad ac Amser ..………………………………………………………....

Appendix F
IPAQ-pr: Consent Form- Proxy Respondents

<u>Consent</u>

Purpose:
The purpose of this study is to assess the levels of physical activity in adults with intellectual disabilities. We are also interested in assessing how well the proxy respondent version of the International Physical Activity Questionnaire (IPAQ-pr) works as a tool for measuring physical activity in adults with ID.

Procedure:
If you agree to take part in this study you will be required to record the exercise schedule for an IDD participant using the IPAQ questionnaire. The experiment will take place over a week and you will be required to complete the questionnaire for the entire week.

Benefits/Risks to the participant:
We do not anticipate that there will be any risk to you from filling out the questionnaires. Whilst there will be no direct benefits to you, the study will help us to get a better picture of the exercise patterns of people with learning disabilities.

Voluntary Nature of the Study/ Confidentiality
It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact any other aspect of your relationship with Bangor University. All data collected will be confidential, and you will not be identifiable in any report, thesis or publication which arises from this study. The data from this study will be stored securely for (5 years). If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

Statement of Consent:
I have read the above information. I understand the experimental procedure and am satisfied and hereby give my consent to participate in this study.

Name of Participant_____Date:_____.

Signature of Participant_____.

Thank you for Participating

Cydsyniad

Pwrpas:
Pwrpas yr astudiaeth hon yw pwyso a mesur lefelau gweithgaredd corfforol yn achos oedolion ag anableddau deallusol. Mae gennym hefyd ddiddordeb yn y modd y mae fersiwn y dirprwy ymatebydd ar gyfer yr Holiadur Rhyngwladol ar Weithgaredd Corfforol (IPAQ-pr) yn gweithio fel offeryn ar gyfer mesur gweithgaredd corfforol ymysg oedolion ag Anableddau Deallusol.

Y Drefn:
Os cytunwch i gymryd rhan yn yr astudiaeth hon, bydd gofyn ichi gofnodi'r rhaglen ymarfer ar gyfer cyfranogwr ag Anabledd Deallusol a Datblygiadol gan ddefnyddio holiadur IPAQ. Cynhelir yr arbrawf dros wythnos, a bydd yn ofynnol ichi lenwi'r holiadur am yr wythnos gyfan. Gofynnir hefyd ichi lenwi'r IPAQ unwaith eto ymhen 8 wythnos.

Buddion/ Risgiau i'r cyfranogwr:
Nid ydym yn rhagweld y bydd unrhyw risg i chi o lenwi'r holiaduron. Er na fydd unrhyw fuddion uniongyrchol i chi, bydd yr astudiaeth yn gymorth mawr i ni gael gwell syniad am batrymau ymarfer pobl sydd ag anableddau dysgu.

Cyfranogiad Gwirfoddol yn yr Astudiaeth / Cyfrinachedd
Mater i chi yw penderfynu p'un a hoffech gymryd rhan yn yr astudiaeth hon neu beidio. Os penderfynwch beidio â chymryd rhan, ni chaiff hynny unrhyw effaith ar eich cysylltiad â Phrifysgol Bangor. Bydd unrhyw ddata a gesglir yn gyfrinachol, ac ni fydd modd eich adnabod mewn unrhyw adroddiad, thesis na chyhoeddiad a fo'n deillio o'r astudiaeth hon. Cedwir y data o'r astudiaeth hon yn ddiogel am (5 mlynedd). Os penderfynwch roi'r gorau i'r astudiaeth, a bod modd i'r tîm ymchwil adnabod eich data, mae gennych hawl i ofyn am beidio â defnyddio eich data.

Datganiad Cydsyniad:
Rwyf wedi darllen y wybodaeth uchod. Deallaf y drefn arbrofol ac yn fodlon, a rhoddaf trwy hyn fy nghydsyniad i gymryd rhan yn yr astudiaeth hon.

Enw'r Cyfranogwr _____ Dyddiad:

Llofnod y Cyfranogwr
_____.

Diolch am Gymryd Rhan.

Appendix G
Adaptive Behavior Assessment System (2nd Edition; ABAS-II)

ABAS II
Adaptive Behavior Assessment System
SECOND EDITION

Patti L. Harrison
Thomas Oakland

Adult Form

Ages 16–89

ADULT INFORMATION

Name of Adult Being Evaluated: _____ Age: _____
First   Middle   Last

Sex: ☐ Female ☐ Male

Education in Years: _____

Occupation: _____

	Month	Day	Year
Today's Date			
Date of Birth			

Does the adult being evaluated have any disabling conditions? ☐ Yes ☐ No

If yes, please describe: _____

Race/Ethnicity:
☐ African American ☐ Asian ☐ Native American
☐ Hispanic ☐ White ☐ Other: _____

Job Status:
☐ No job ☐ Part-time job ☐ Full-time job
☐ Other: _____

RATER INFORMATION

Rater's Name: _____ Age: _____ Occupation: _____
First   Last

Your relationship to the individual you are rating:

☐ Self ☐ Parent ☐ Spouse ☐ Partner
☐ Sibling ☐ Child ☐ Other Relative, describe: _____
☐ Roommate ☐ Friend ☐ Teacher ☐ Supervisor
☐ Professional Caregiver ☐ Other, describe: _____

W-489A

Directions

The *Adaptive Behavior Assessment System–Second Edition* is designed to measure important behaviors an individual displays at home, school, work, and other settings. The behaviors included on this scale range from those suitable for young children to those suitable for adults. Some items may seem too difficult for the individual while others may seem too easy. Therefore, the individual you are rating is likely to display some but not all behaviors included on this scale.

Please read and answer ALL items

Rate the individual according to how often he or she **correctly** performs a behavior, **without help**, when the behavior needs to be displayed. The rating you choose should reflect the frequency with which the individual performs the behavior without help, when it is needed. Record your response for each item by circling one of the following:

0	Is Not Able
1	Never or Almost Never When Needed
2	Sometimes When Needed
3	Always or Almost Always When Needed

Then evaluate whether you have observed the behavior or if you are guessing about the frequency of its occurrence. If your rating is based on a guess, put a check (✓) in the box marked **Check If You Guessed**. If your answer is based on observation or direct knowledge, leave this column blank.

The following example shows how to complete the Rating Form:

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed
4. Uses sentences with a noun and a verb.	0	1	2	③	☐
5. States home address, including zip code.	0	1	②	3	✓
6. Answers the telephone appropriately.	⓪	1	2	3	☐

In the example above, the individual being rated **Always** (or Almost Always) uses sentences with a noun and a verb when needed; **Sometimes** states home address, including zip code; and **Is Not Able** to answer the telephone appropriately. The ratings of Items 4 and 6 are based on observation or direct knowledge; therefore the **Check If You Guessed** column is left blank. The rater guessed on Item 5, so the **Check If You Guessed** column is marked.

②

he following table is provided to further assist you in filling out this form.

Rating	The individual:
0 Is Not Able	• cannot perform the behavior; • is too young to have tried the behavior; or • has a physical condition that prevents the behavior.
1 Never or Almost Never When Needed	has the ability to perform the behavior, but • never or almost never does it when needed; or • never or almost never does it on his/her own without being reminded.
2 Sometimes When Needed	has the ability to perform the behavior, and • only does it sometimes when needed; • sometimes does it without help, but sometimes needs help; or • sometimes does it on his/her own, but sometimes needs to be reminded.
3 Always or Almost Always When Needed	has the ability to perform the behavior, and • displays the behavior most or all of the time without being reminded; or • displayed the behavior at a younger age, but has now outgrown it.

Column	Check this column if:
Check If You Guessed	• your rating was an estimate. • you have never seen the individual in a situation in which the behavior is needed. • the individual has not had the opportunity to perform the behavior.
Comments	• you do not understand an item.* • you feel it would be helpful to discuss an item with the assessment professional.*

You may make a brief note of your concerns in the Notes box on page 10 of this Rating Form.

			BEHAVIOR FREQUENCY				
Communication		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1.	Says the names of other people, for example, "Mama," "Daddy," or friends' names.	0	1	2	3	☐	○
2.	Says "Hello" and "Good-bye" to others.	0	1	2	3	☐	○
3.	States his/her own telephone number.	0	1	2	3	☐	○
4.	Uses sentences with a noun and a verb.	0	1	2	3	☐	○
5.	States home address, including zip code.	0	1	2	3	☐	○
6.	Answers the telephone appropriately.	0	1	2	3	☐	○
7.	Names 20 or more familiar objects.	0	1	2	3	☐	○
8.	Places local telephone calls.	0	1	2	3	☐	○
9.	Speaks clearly and distinctly.	0	1	2	3	☐	○
10.	Gives verbal instructions that involve two or more steps or activities.	0	1	2	3	☐	○
11.	Looks at others' faces when they are talking.	0	1	2	3	☐	○
12.	Shakes head or says "yes" or "no" in response to a simple question, for example, "Do you want something to drink?"	0	1	2	3	☐	○
13.	Ends conversations appropriately.	0	1	2	3	☐	○
14.	Tells parents, friends, or others about his/her favorite activities.	0	1	2	3	☐	○
15.	Says irregular plural nouns, for example, knives or mice.	0	1	2	3	☐	○
16.	Listens closely for at least five minutes when people talk.	0	1	2	3	☐	○

③

ABAS–II ADULT (Ages 16–89)

			BEHAVIOR FREQUENCY			
Communication continued		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed
17. Pays attention during family or group discussions for as long as needed.		0	1	2	3	☐
18. Nods or smiles to encourage others when they are talking.		0	1	2	3	☐
19. Uses up-to-date information to discuss current events.		0	1	2	3	☐
20. Starts conversations on topics of interest to others.		0	1	2	3	☐
21. Repeats stories or jokes after hearing them from others.		0	1	2	3	☐
22. Waits for a pause in a conversation before expressing his/her own ideas.		0	1	2	3	☐
23. Answers complex questions that require careful thoughts and opinions, for example, questions about politics or current events.		0	1	2	3	☐
24. Talks about realistic future educational or career goals.		0	1	2	3	☐
25. Takes turns talking during conversations with people (is not too talkative or too quiet).		0	1	2	3	☐

Total _____ / 75 Total Guessed

Community Use

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed
1. Orders his/her own meals when eating out.	0	1	2	3	☐
2. Finds the restrooms in public places.	0	1	2	3	☐
3. Looks both ways before crossing a street or parking lot.	0	1	2	3	☐
4. Carries enough money to make small purchases, for example, a soft drink.	0	1	2	3	☐
5. Carries personal identification when traveling to nearby places in the community.	0	1	2	3	☐
6. Finds a specific department in a store or business, for example, customer service department in a bank or laundry supplies in a store.	0	1	2	3	☐
7. Relies on himself/herself for travel in the community, for example, walks or uses public transportation, a bicycle, or a car.	0	1	2	3	☐
8. Packs his/her own clothing and supplies for overnight trips.	0	1	2	3	☐
9. Mails letters at the postal box or local post office.	0	1	2	3	☐
10. States general address of a travel destination, for example, "On Washington Avenue, near Lake Street."	0	1	2	3	☐
11. Follows another's directions to nearby places.	0	1	2	3	☐
12. Finds and uses a pay phone.	0	1	2	3	☐
13. Asks store clerk for help if an item cannot be found.	0	1	2	3	☐
14. Tells others about a store's hours of operation, for example, "10 a.m. to 9 p.m."	0	1	2	3	☐
15. Walks alone to friends' houses in the neighborhood.	0	1	2	3	☐
16. Calls a doctor or hospital when ill or hurt.	0	1	2	3	☐
17. Calls to find out if a repair or order is ready.	0	1	2	3	☐
18. Calls a repairperson if, for example, the air conditioner or heater is not working.	0	1	2	3	☐
19. Takes other people on trips to nearby places, for example, takes a child or family member to a park.	0	1	2	3	☐
20. Asks other people's advice on where to shop.	0	1	2	3	☐
21. Shops for friends and family who may be unable to shop.	0	1	2	3	☐
22. Walks or rides bike alone to locations within a one-mile or five-block radius of home or work.	0	1	2	3	☐
23. Uses the local library to check out books, use reference materials, or for other purposes.	0	1	2	3	☐
24. Asks store clerk for product information before buying an item.	0	1	2	3	☐

Total _____ / 72 Total Guessed

④

Functional Academics

	In Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Writes his/her own first and last name.	0	1	2	3	☐	○
2. Reads his/her own written name.	0	1	2	3	☐	○
3. States the days of the week in order.	0	1	2	3	☐	○
4. Tells time correctly, using a watch or a clock with hands.	0	1	2	3	☐	○
5. Gives clerk the necessary amount of money when purchasing items.	0	1	2	3	☐	○
6. Writes his/her own address, including zip code.	0	1	2	1	☐	○
7. Reads and obeys common signs, for example, Do Not Enter, Exit, or Stop.	0	1	2	3	☐	○
8. Reads menus at restaurants.	0	1	2	1	☐	○
9. Finds somebody's telephone number in the phone book.	0	1	2	1	☐	○
10. States time and day of favorite television shows.	0	1	2	1	☐	○
11. Reads and follows a daily work or other type of schedule.	0	1	2	3	☐	○
12. Locates important dates on a calendar, for example, birthdays or holidays.	0	1	2	1	☐	○
13. Weighs himself/herself or other objects correctly using a scale.	0	1	2	3	☐	○
14. Measures length and height.	0	1	2	1	☐	○
15. Finds name and phone number in telephone book for repair service or business.	0	1	2	3	☐	○
16. Checks for correct change after buying an item.	0	1	2	1	☐	○
17. Follows a favorite interest or current event by reading newspapers, books, or other materials.	0	1	2	3	☐	○
18. Keeps score when playing games.	0	1	2	3	☐	○
19. Uses a dictionary or encyclopedia to find information.	0	1	2	3	☐	○
20. Reads and follows instructions to assemble new purchases.	0	1	2	3	☐	○
21. Writes letters, notes, or e-mails.	0	1	2	3	☐	○
22. Makes reminder notes or lists.	0	1	2	1	☐	○
23. Completes forms for businesses or services, for example, obtains a lease.	0	1	2	3	☐	○
24. Reads important documents, for example, credit card applications or rental agreements.	0	1	2	1	☐	○
25. Budgets money to cover expenses for at least one week.	0	1	2	3	☐	○
26. Reads classified ads for purchases and services.	0	1	2	1	☐	○
27. Balances checkbook.	0	1	2	3	☐	○

Total ____ / B1 Total Guessed

Home Living

	In Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Operates a microwave oven.	0	1	2	3	☐	○
2. Uses small electrical appliances, for example, a can opener or blender.	0	1	2	3	☐	○
3. Cooks simple foods on a stove, for example, eggs or canned soup.	0	1	2	3	☐	○
4. Makes simple meals that require no cooking, for example, sandwiches or salads.	0	1	2	3	☐	○
5. Wipes up spills at home.	0	1	2	3	☐	○
6. Places dirty clothes in the proper place, for example, a hamper or clothesbasket.	0	1	2	3	☐	○
7. Wipes wet or dirty shoes before entering a building.	0	1	2	3	☐	○
8. Washes dishes either by hand or by placing them in a dishwasher.	0	1	2	3	☐	○
9. Uses a clothes dryer.	0	1	2	3	☐	○

③

ABAS–II ADULT (Ages 16–89)

		BEHAVIOR FREQUENCY				
Home Living *continued*	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
10. Uses a washing machine to wash clothes.	0	1	2	3	☐	○
11. Assists in big clean-up projects at home or work, for example, spring cleaning or cleaning storage rooms.	0	1	2	3	☐	○
12. Folds clean clothes.	0	1	2	3	☐	○
13. Takes out trash when can is full.	0	1	2	3	☐	○
14. Clears the table completely after a meal.	0	1	2	3	☐	○
15. Makes his/her own bed.	0	1	2	3	☐	○
16. Makes minor repairs to personal possessions, for example, bikes or clothes.	0	1	2	3	☐	○
17. Puts things in their proper place when finished using them.	0	1	2	3	☐	○
18. Sweeps floor.	0	1	2	3	☐	○
19. Cleans room or living quarters regularly.	0	1	2	3	☐	○
20. Cleans bathroom with proper cleaning supplies.	0	1	2	3	☐	○
21. Mixes and cooks fairly complex foods on a stove or oven, for example, cake or brownies.	0	1	2	3	☐	○
22. Dusts furniture until it is clean.	0	1	2	3	☐	○
23. Follows a maintenance schedule for home or car, for example, changes the oil in the car or changes the air conditioning filter.	0	1	2	3	☐	○

Total / 69 Total Guessed

Health and Safety

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Swallows liquid medicines if needed for illness.	0	1	2	3	☐	○
2. Shows caution around hot or dangerous items.	0	1	2	3	☐	○
3. Uses electrical outlets or sockets safely.	0	1	2	3	☐	○
4. Goes to another place when too hot or too cold, for example, finds shade if too hot, goes indoors when too cold.	0	1	2	3	☐	○
5. Carries breakable objects safely and carefully.	0	1	2	3	☐	○
6. Follows general safety rules at home.	0	1	2	3	☐	○
7. Follows safety rules for fire or weather alarms at home or work.	0	1	2	3	☐	○
8. Follows general safety regulations at work or other public places.	0	1	2	3	☐	○
9. Takes prescription medicines by himself/herself.	0	1	2	3	☐	○
10. Cares for his/her minor injuries, for example, paper cuts, knee scrapes or nosebleeds.	0	1	2	3	☐	○
11. Tests hot foods before eating them.	0	1	2	3	☐	○
12. Carries scissors safely.	0	1	2	3	☐	○
13. Follows safety rules at park or playground.	0	1	2	3	☐	○
14. Buckles his/her seat belt in a car.	0	1	2	3	☐	○
15. Obeys traffic signals when riding a bike or driving a car.	0	1	2	3	☐	○
16. Buys over-the-counter medications when needed for illness.	0	1	2	3	☐	○
17. Stores poisonous substances or dangerous objects out of the reach of children.	0	1	2	3	☐	○
18. Helps children cross the street by taking their hands.	0	1	2	3	☐	○
19. Takes temperature with a thermometer when feeling sick.	0	1	2	3	☐	○
20. Plans meals in order to get necessary nutrition.	0	1	2	3	☐	○

Total / 60 Total Guessed

ABAS-II ADULT (Ages 16-89)

Leisure

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed	Comments
1. Waits for his/her turn in games and other fun activities.	0	1	2	3	☐	○
2. Selects television programs or videotapes to keep up with an area of interest, for example, sports, music, or nature.	0	1	2	3	☐	○
3. Follows the rules in games and other fun activities.	0	1	2	3	☐	○
4. Listen to music for fun and relaxation.	0	1	2	3	☐	○
5. Looks at pictures or reads books or magazines during free time.	0	1	2	3	☐	○
6. Invites others to join him/her in playing games and other fun activities.	0	1	2	3	☐	○
7. Attends fun activities at another's home.	0	1	2	3	☐	○
8. Plays with toys, games, or other fun items with other people.	0	1	2	3	☐	○
9. Tells others when he/she needs free time to relax alone.	0	1	2	3	☐	○
10. Attends fun community activities with others, for example, a movie or concert.	0	1	2	3	☐	○
11. Decides alone to participate with others playing a game or other group activity.	0	1	2	3	☐	○
12. Plans ahead for play or fun activities on free days or afternoons.	0	1	2	3	☐	○
13. Initiates games or selects TV programs liked by friends or family members.	0	1	2	3	☐	○
14. Participates in a specific fun activity on a routine basis, for example, listening to a certain type of music or playing a computer game.	0	1	2	3	☐	○
15. Plans ahead for leisure activities during work, school breaks, or vacations.	0	1	2	3	☐	○
16. Plays alone with toys, games, or other fun activities.	0	1	2	3	☐	○
17. Invites others home for a fun activity.	0	1	2	3	☐	○
18. Organizes a game or other fun activity for a group of friends without help from others.	0	1	2	3	☐	○
19. Tries a new activity to learn about something new.	0	1	2	3	☐	○
20. Has a hobby or creative activity that requires making or building something, for example, sewing, carpentry, or gardening.	0	1	2	3	☐	○
21. Reserves tickets in advance for activities, for example, concerts or sports events.	0	1	2	3	☐	○
22. Decides alone to join an organized group, for example, a club, sports team, or musical group.	0	1	2	3	☐	○
23. Participates in an organized program for a sport or hobby, for example, takes a music class or practices basketball.	0	1	2	3	☐	○

Total ___ / 69 Total Guessed

Self-Care

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed	Comments
1. Puts shoes on correct feet.	0	1	2	3	☐	○
2. Blows and wipes nose with tissue or handkerchief.	0	1	2	3	☐	○
3. Buttons his/her own clothing.	0	1	2	3	☐	○
4. Dresses himself/herself.	0	1	2	3	☐	○
5. Uses restroom at home without help.	0	1	2	3	☐	○
6. Washes hands with soap.	0	1	2	3	☐	○
7. Uses a fork to eat solid food.	0	1	2	3	☐	○
8. Ties his/her own shoes.	0	1	2	3	☐	○
9. Combines hot and cold water for shower or bath.	0	1	2	3	☐	○
10. Closes and locks door before using public restrooms.	0	1	2	3	☐	○

⑦

ABAS-II ADULT (Ages 16–89)

Self-Care continued

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed	Comments
11. Uses public restroom alone.	0	1	2	3	☐	○
12. Washes his/her own hair.	0	1	2	3	☐	○
13. Fastens and straightens clothing before leaving restroom.	0	1	2	3	☐	○
14. Selects correct clothes for cold or warm days.	0	1	2	3	☐	○
15. Cleans or brushes himself/herself off if muddy or dirty.	0	1	2	3	☐	○
16. Brushes teeth before leaving for work or appointments.	0	1	2	3	☐	○
17. Bathes daily.	0	1	2	3	☐	○
18. Keeps hair neat during the day by brushing or combing.	0	1	2	3	☐	○
19. Cuts meats or other foods into bite size pieces.	0	1	2	3	☐	○
20. Cleans under fingernails.	0	1	2	3	☐	○
21. Gets out of bed on time by himself/herself.	0	1	2	3	☐	○
22. Cuts or files his/her own fingernails and toenails on a regular basis.	0	1	2	3	☐	○
23. Has pleasant breath.	0	1	2	3	☐	○
24. Washes and rinses sink after brushing teeth.	0	1	2	3	☐	○
25. Gets hair cut.	0	1	2	3	☐	○

Total / 75 Total Guessed

Self-Direction

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed	Comments
1. Keeps spending money in pocket, purse, or other safe place.	0	1	2	3	☐	○
2. Works independently and asks for help only when necessary.	0	1	2	3	☐	○
3. Works on one home activity for at least 15 minutes.	0	1	2	3	☐	○
4. Goes out alone in daytime.	0	1	2	3	☐	○
5. Avoids situations at home or in the neighborhood that are likely to result in trouble.	0	1	2	3	☐	○
6. Stops a fun activity, without complaints, when time is up.	0	1	2	3	☐	○
7. Personally calls work or other places if absent.	0	1	2	3	☐	○
8. Completes routine household tasks within a reasonable amount of time.	0	1	2	3	☐	○
9. Controls anger when another person breaks the rules in games and other fun activities.	0	1	2	3	☐	○
10. Refrains from telling a lie to escape punishment.	0	1	2	3	☐	○
11. Routinely arrives at places on time.	0	1	2	3	☐	○
12. Controls disappointment when a favorite activity is canceled.	0	1	2	3	☐	○
13. Controls temper when disagreeing with friends.	0	1	2	3	☐	○
14. Keeps working on hard tasks without becoming discouraged or quitting.	0	1	2	3	☐	○
15. Saves money to buy something special, for example, a birthday present or special clothes.	0	1	2	3	☐	○
16. Cancels fun activity if something more important comes up.	0	1	2	3	☐	○
17. Returns on time when requested to be back in one hour.	0	1	2	3	☐	○
18. When leaving home, informs others of destination and return time.	0	1	2	3	☐	○
19. Controls feelings when not getting his/her own way.	0	1	2	3	☐	○

⑥

ABAS–II ADULT (Ages 16–89)

		BEHAVIOR FREQUENCY				
Self-Direction continued	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
20. Puts work or school over leisure activities.	0	1	2	3	☐	○
21. Plans ahead to allow enough time to complete big projects.	0	1	2	3	☐	○
22. Makes plans for home projects in logical steps.	0	1	2	3	☐	○
23. Gathers all supplies needed before beginning a cleaning or maintenance project at home.	0	1	2	3	☐	○
24. Calls family or others when late.	0	1	2	3	☐	○
25. Completes large home projects on time.	0	1	2	3	☐	○
Total				/75 Total Guessed		

Social

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Says "Thank you" when given a gift.	0	1	2	3	☐	○
2. Has one or more friends.	0	1	2	3	☐	○
3. Laughs in response to funny comments or jokes.	0	1	2	3	☐	○
4. Stands a comfortable distance from others during conversations (not too close).	0	1	2	3	☐	○
5. Moves out of another person's way without being asked.	0	1	2	3	☐	○
6. Offers assistance to others.	0	1	2	3	☐	○
7. Congratulates others when something good happens to them.	0	1	2	3	☐	○
8. Keeps a stable group of friends.	0	1	2	3	☐	○
9. Seeks friendships with others in his/her age group.	0	1	2	3	☐	○
10. Has good relationships with family members.	0	1	2	3	☐	○
11. Shows sympathy for others when they are sad or upset.	0	1	2	3	☐	○
12. Places reasonable demands on friends, for example, does not become upset when a friend goes out with another friend.	0	1	2	3	☐	○
13. Offers guests food or beverages.	0	1	2	3	☐	○
14. Shows good judgment in selecting friends.	0	1	2	3	☐	○
15. Listens to friends or family members who need to talk about problems.	0	1	2	3	☐	○
16. Offers to lend belongings to others, for example, clothes or tools.	0	1	2	3	☐	○
17. Apologizes if he/she hurts the feelings of others.	0	1	2	3	☐	○
18. Compliments others for good deeds or behavior, for example, honesty or kindness.	0	1	2	3	☐	○
19. Tries to please others by doing something special or giving them a surprise.	0	1	2	3	☐	○
20. States when others seem happy, sad, scared, or angry.	0	1	2	3	☐	○
21. Refrains from saying something that might embarrass or hurt others.	0	1	2	3	☐	○
22. Personally makes or buys gifts for family members on birthdays or major holidays.	0	1	2	3	☐	○
23. Says when he/she feels happy, sad, scared, or angry.	0	1	2	3	☐	○
Total				/69 Total Guessed		

⑨

ABAS-II ADULT (Ages 16-85)

Work

Complete the **Work** skill area if the individual being rated holds a part-time or full-time job.

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check if You Guessed	Comments
1. Respects the property and rights of other workers.	0	1	2	3	☐	○
2. Attends work regularly.	0	1	2	3	☐	○
3. Follows daily work schedule without reminders from supervisor.	0	1	2	3	☐	○
4. Behaves safely at work so that no one will be harmed.	0	1	2	3	☐	○
5. Performs tasks at work neatly.	0	1	2	3	☐	○
6. Cares properly for work supplies and equipment.	0	1	2	3	☐	○
7. Works faster on the job as needed, for example, to keep on schedule or meet a deadline.	0	1	2	3	☐	○
8. Cleans up area after completing work.	0	1	2	3	☐	○
9. Returns tools and other work-related items to their proper location after their use.	0	1	2	3	☐	○
10. Completes work assignments in required time limits.	0	1	2	3	☐	○
11. Starts back to work willingly after taking a break or lunch.	0	1	2	3	☐	○
12. Chooses work consistent with his/her own skills and abilities.	0	1	2	3	☐	○
13. Works quietly and does not disrupt or disturb the work of others.	0	1	2	3	☐	○
14. Changes from one job-related task to another without special instructions from supervisor.	0	1	2	3	☐	○
15. Checks his/her own work to determine if improvements are needed.	0	1	2	3	☐	○
16. Finds full-time or part-time jobs for himself/herself.	0	1	2	3	☐	○
17. Performs extra work on the job willingly.	0	1	2	3	☐	○
18. Asks for directions, as needed, before beginning work tasks.	0	1	2	3	☐	○
19. Keeps working quickly and accurately, even with loud noises or distractions.	0	1	2	3	☐	○
20. Follows supervisor's suggestions to improve work.	0	1	2	3	☐	○
21. Helps other workers with their work without interfering with his/her own work.	0	1	2	3	☐	○
22. Seeks help from supervisor, as needed, when work-related problems or questions arise.	0	1	2	3	☐	○
23. Shows positive attitude towards job.	0	1	2	3	☐	○
24. Lives on his/her own earnings.	0	1	2	3	☐	○

Total ___ / 72   Total Guessed

Notes:

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ABAS-II ADULT (Ages 16-89)

ABAS II
Adaptive Behavior
Assessment System
SECOND EDITION

Supplemental Analyses

Calculate the Skill Area Mean Scaled Scores

	9 Skill Areas (GAC w/o Work)	10 Skill Areas (GAC w/ Work)	Conceptual Domain	Practical Domain (w/o Work)	Practical Domain (w/ Work)
Sum of Scaled Scores					
Number of Skill Areas	÷ 9	÷ 10	÷ 3	÷ 4	÷ 5
Mean Scaled Score					

Determine Strengths and Weaknesses

Domain	Skill Areas	Skill Area Scaled Score	Mean Scaled Score	Difference from Mean	Critical Value	Strength or Weakness (S) or (W)	Base Rate in Standardization Sample
CON	Communication						
CON	Functional Academics						
CON	Self-Direction						
SO	Leisure						
SO	Social						
PR	Community Use			-			
PR	Home Living						
PR	Health and Safety						
PR	Self-Care						
PR	Work						

Comparison Group
☐ GAC Mean
☐ Domain Means

Statistical Significance Level
☐ .15
☐ .05

To determine strengths and weaknesses (Self Report) see Table B.15 (GAC Mean), or Tables B.13, B.16, and B.17 (Domain Means).
To determine strengths and weaknesses (Rated by Others) see Table B.22 (GAC Mean) or Tables B.23, B.23, and B.24 (Domain Means).

Discrepancy Comparisons

Domain Composite	Score 1	Score 2	Difference	Critical Value	Significant Difference (Y) or (N)	Base Rate in Standardization Sample
Conceptual–Social	CON	SO				
Conceptual–Practical	CON	PR				
Social–Practical	SO	PR				

Statistical Significance Level
☐ .15
☐ .05

For discrepancy comparisons (Self Report) see Tables B.19 and B.20.
For discrepancy comparisons (Rated by Others) see Tables B.26 and B.27.

Percent of cases under portions of the normal curve							
Percent of Cases	2.2	6.7	16.1	50	16.1	6.7	2.2
Standard Scores	70	80	90	100	110	120	130
Qualitative Descriptions	Extremely Low	Borderline	Below Average	Average	Above Average	Superior	Very Superior
GAC/Composite Score Ranges	≤70	71–79	80–89	90–109	110–119	120–129	≥130

⑪

ABAS II

Adaptive Behavior
Assessment System
SECOND EDITION
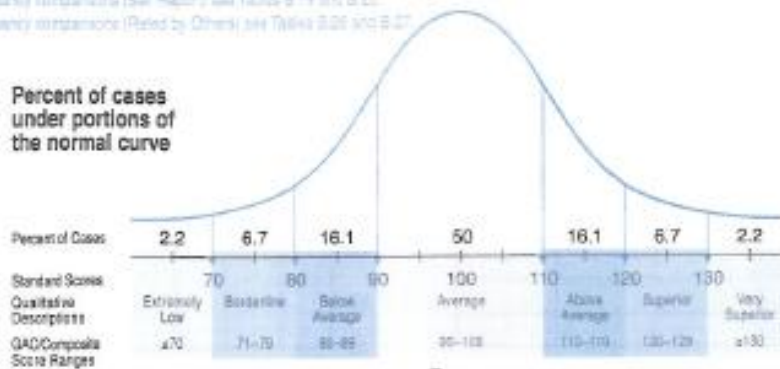
Summary Page

Patti L. Harrison · Thomas Oakland

ABAS–II ADULT (Ages 16–89)

Adult's Name: _____
          First   Middle   Last

ID: _____

Rater's Name: _____

Assessment Professional: _____

	Year	Month	Day
Today's Date			
Date of Birth			
Age			

Raw Score to Scaled Score Conversions
See Table A.9 (Self Report) or Table A.12 (Rated by Others).

Skill Areas		Raw Scores	Scaled Scores
Communication	(Com)		
Community Use	(CU)		
Functional Academics	(FA)		
Home Living	(HL)		
Health and Safety	(HS)		
Leisure	(LS)		
Self-Care	(SC)		
Self-Direction	(SD)		
Social	(Soc)		
(Work)	(WK)	( )	( )

Sums of Scaled Scores

Composite   GAC   CON   SO   PR

Sum of Scaled Scores to Composite Score Conversions
See Table A.10 (Self Report) or Table A.13 (Rated by Others).

Composite	Sum of Scaled Scores	Composite Score	Percentile Rank	___% Confidence Interval
GAC				–
Conceptual				–
Social				–
Practical				–

Skill Area Scaled Score Profile

	Conceptual			Social		Practical				
	Com	FA	SD	LS	Soc	CU	HL	HS	SC	WK
19	·	·	·	·	·	·	·	·	·	·
18	·	·	·	·	·	·	·	·	·	·
17	·	·	·	·	·	·	·	·	·	·
16	·	·	·	·	·	·	·	·	·	·
15	·	·	·	·	·	·	·	·	·	·
14	·	·	·	·	·	·	·	·	·	·
13	·	·	·	·	·	·	·	·	·	·
12	·	·	·	·	·	·	·	·	·	·
11	·	·	·	·	·	·	·	·	·	·
10	·	·	·	·	·	·	·	·	·	·
9	·	·	·	·	·	·	·	·	·	·
8	·	·	·	·	·	·	·	·	·	·
7	·	·	·	·	·	·	·	·	·	·
6	·	·	·	·	·	·	·	·	·	·
5	·	·	·	·	·	·	·	·	·	·
4	·	·	·	·	·	·	·	·	·	·
3	·	·	·	·	·	·	·	·	·	·
2	·	·	·	·	·	·	·	·	·	·
1	·	·	·	·	·	·	·	·	·	·

Composite Score Profile

GAC	CON	SO	PR

160
150
140
130
120
110
100
90
80
70
60
50
40

⑫
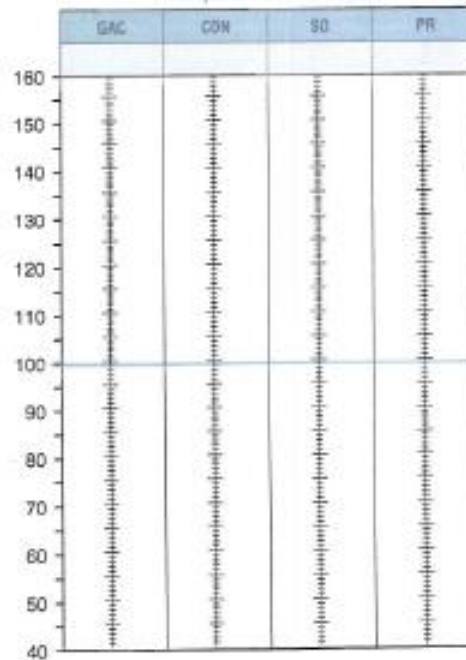
Appendix H
OK Health Check

OK
Health Check.

For assessing and planning the health care needs of people with learning disabilities

Name:	....
Address:	....
	....
	....
Date:	....

Service User's Age:	Gender:

Has the service user been diagnosed as having a particular clinical syndrome or congenital condition?

Date of previous health check: ……………………………………………….

Date of this health check: ………………………………………………………

Name of Assessor: …………………………………………………

Date of most recent full medical examination: …………………………………...

Doctor who conducted the above examination: …………………………………..

Body Measurements   **Difference +/-**

Weight last time:	Weight Now:	
Height Last time:	Height Now:	
Waist last time:	Waist now:	

Body mass	Yes	No	Don't know
Do you consider the service user to be overweight?			
Do you consider the service user to be underweight?			

Please comment on the above as appropriate.

Current Medication   **Dosage**

Please list known potential side effects of the above medication for which staff should be alerted to observe.

Date of last medication review: …………………………………………………

Doctor who conducted the review ………………………………………

Pain	Yes	No	Don't know
When the service user experiences pain or discomfort, is he/she able to express it? Please give details below.			
Does the service user appear to suffer any particular pain or discomfort, frequently, occasionally or periodically?			

Please give additional details of the above items.

Circulation and breathing	Pulse.	Resp.	BP
Pulse, breathing and blood pressure at rest.			
	Yes	No	Don't know
Does the service user show any signs of oedema?			
Does the service user ever show signs of cyanosis?			
Do the service user's fingers show signs of cardio-pulmonary disorder?			
Does the service user suffer difficulty breathing or have a troublesome cough?			
Is the service user known to have any congenital or chronic circulatory or respiratory disorder?			
Does the service user have varicose veins?			

Comment on the above.

Details of any investigations

Urinary system	Yes	No	Don't know
Is the service user incontinent by day or night?			
Has the pattern if incontinence changed recently?			
Does the service user appear to have any problem passing urine?			
Does the service user's urine appear abnormally coloured or smell offensive?			

Please give details of any of the above

Epilepsy	Yes	No	Don't know
Does the service user have any form of epilepsy?			
Is an accurate record or seizures maintained?			
According to those records, has there been any change in the frequency or pattern of seizures recently?			
Does the service user receive anti-convulsant medication?			
If yes, does this medication require blood tests?			
Are all staff fully aware of the various potential side effects of the service users anti-convulsant medication?			

Please give details for any of the above and provide dates as appropriate, state factors that are known to exacerbate this service user's epilepsy.

Date of last anti-convulsant medication review ………………………………………..

Date of last anti-convulsant blood level test …………………………………………...

Digestion and Elimination	Yes	No	Don't know
Is the service user's diet obviously deficient in any way? Give details below.			
Does the service user receive a 'special' diet for any reason? Give details below.			
Does the service user drink adequate fluids?			
Does the service user frequently suffer constipation or loose motions?			
Does the service user pass abnormally coloured motions? Give details below.			
Does the service user appear to suffer frequent discomfort that might originate in the digestive system or bowel?			

	Yes	No	Don't know
Does the service user have any known chronic digestive condition?			
Does the service user appear to experience any difficulties or reluctance to eat, or have any peculiar eating habits?			

Please give details of the above, including any investigations

Date of last review of special diet by doctor or dietician …………………………….

Skin	Yes	No	Don't know
Does the service user have any rash, irritation or itching?			
Does the service user have any moles or other marks that were not evident at the last assessment, or which have changed?			
Do the service users pressure areas become inflamed?			
Does the service user have any damaged or broken skin?			
Does the service user have any chronic or long standing skin condition?			
Does the service user suffer offensive body odour or other personal hygiene problem?			

Provide further details of above including any investigations.

 In your own words, describe the service user's complexion.

Physique and mobility	Yes	No	Don't know
Is the service user permanently physically handicapped? If yes please give details blow of the extent and nature of this.			
Is the service user's gross motor activity and dexterity impaired?			
Does the service user have difficulty coordinating movement and/or hand-eye coordination?			
Does the service user have a persistently poor posture? Comment on stooping and spinal curvatures.			
Does the service user have contracture problems?			
Is there any evidence of tremors, twitches or other uncontrolled movements?			
Does the service user suffer any myoclonic spasms?			
Does there appear to be any particular loss of movement or pain on movement? Comment below			
Does the service user have any muscle wasting?			
Does the service user have any mobility or positioning aids? If yes please comment on their use and condition.			

Physiotherapy	Yes	No	Don't know
Does the service user receive services from a physiotherapist?			

Comment on the above 'Physique and mobility' items and provide further details as appropriate.

State if attention is needed to any aids used by? Or which might be useful to this service user.

Date of last physiotherapy review: ……………………………………….

Name of physiotherapist: …………………………………………………

Feet	Yes	No	Don't know
Is there an obvious problem in relation to the shape of the feet?			
Is there evidence of skin problems on the feet or between the toes, any signs if itching or discomfort?			
Are the toe nails thick, misshapen or abnormal?			
Does the service user appear to have any pain in the feet?			
Is there any evidence of circulation problems to the feet?			
Is a chiropodist involved in the service user's foot care?			

Comment on the above.

Date of last chiropodist appointment: …………………..

Name of chiropodist: …………………………………………………..

Oral hygiene

	Yes	No	Don't know
Does the service user have regular dental checks?			
Does the service user have any teeth? Comment below.			
Is there any obvious problem with teeth or gums?			
Does the service user have any difficulty chewing?			
Does the service user persistently have offensive breath?			
Does the service user dribble excessively?			
Does the services user have any chronic mouth condition?			
Does the services user have frequent mouth sores or ulcers?			
Does the services user appear to have painful or sensitive teeth?			
Does the services user have dentures?			
If yes, does the services user wear them?			

Comment on the above.

.

Date of last dental examination: ………………………………..

Name of dentist: …………………………………

Eyes and vision

	Yes	No	Don't know
Does the services user have any obvious eye/vision defect?			
Does the services user have any obvious opacity of the eyes?			
Is there any behaviour which might suggest the service user has discomfort or other problem or the eyes?			
Is there any behaviour which suggests problems with vision?			
Does the services user appear to suffer discomfort in respect of the eyelids?			
Does the service user wear spectacles? If yes, comment on the condition			
Has the service user had their eyes and vision checked?			

Give details of any of the above eye and vision items.

Date eyes and vision last checked: …………………………………….

Name of ophthalmic practitioner: …………………………………

Ears and hearing

	Yes	No	Don't know
Does the services user have any obvious ear problem?			
Does the services user's behaviour suggest a hearing problem?			
Does the services user have a history of ear problems?			
Does the services user have impacted or excess ear wax?			
Has the services user's ears and hearing being checked?			
Does the services user use a hearing aid? If yes comment on its use and condition.			
Does the services user appear to have any balance problems?			

Comment on the above.

Date of last ear/hearing examination: …………………………….

Sexual health – Female

	Yes	No	Don't know
Has the service user had a breast examination? Give details.			
Has the service user had a cervical smear? Give details.			
Does the service user menstruate regularly?			
Does the service user appear to experience any physical or psychological problems with her menstrual cycle?			
Does the service user appear to have frequent or periodic itching or discomfort of the anus, perineum or genitals?			

Comment on the above and any sexual activity that is likely to benefit from health promotion.

Details of examination: …………………………………………………………………………………………

………...

Sexual health – Male

	Yes	No	Don't know
Has the service user had a testicle/genital examination? Give details.			
Does the service user frequently dribble after passing urine?			
Does the service user appear to have any frequent or periodic itching or discomfort of the anus or genitals.			

Comment on the above and any sexual activity that is likely to benefit from health promotion.

Details of examination: ……………………………………………………………………………

………………………………………………………………………………………………………...

Sleep

	Yes	No	Don't know
Does the service user have a disturbed sleep pattern?			
Does the service user often stay awake much of the night?			
Does the service user often sleep much of the day?			
Does the service user use night sedation to assist sleep?			

Comment on the above

Mental health

	Yes	No	Don't know
Does the service user appear to experience frequent emotional distress?			
Does the service user display apparently irrational mood swings?			
Does the service user appear to experience altered perceptions?			
Does the service user appear to have any irrational fears or anxieties?			
Does the service user indulge in any obsessional behaviour?			
Does the service user suffer form any psychosomatic disorders, or any physical condition that does not appear to have a cause despite investigation?			
Does the service user appear to suffer frequent or periodic headaches?			

Comment on the above.

Date of most recent psychiatric review: ………………………………

Name of psychiatrist: ……………………………………………………

Lifestyle risks

	Yes	No	Don't know
Does the service user take sufficient regular exercise?			
Does the service user indulge in any behaviour likely to threaten health?			
Does the service user have any habits that are likely to pose a threat to health? (Smoking etc).			
Does the service user indulge in self injurious behaviours?			

Comment on the above.

Christopher will go for walk if motivated.

Stressors Detail any specific stressors the service user may currently be experiencing.

Other health issues
Comment on any issues not detailed elsewhere, or elaborate on any issues as necessary.

Summary
Briefly summarise the items which require further action or investigation.

Action plan briefly detail immediate, high priority actions and interventions that are necessary.

Referrals and investigations required

A medication review has been requested

Signed: ……………………………………………………….. Assessor

Signed: ……………………………………………………….. Manager

Appendix I
Health of the Nation Outcome Scales-Learning Disability (HoNOS-LD)

Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS–LD)

Glossary for HoNOS–LD score sheet[†]

ASHOK ROY, HELEN MATTHEWS, PAUL CLIFFORD, VANESSA FOWLER and DAVID M. MARTIN

Summary rating instructions:

(a) Complete the front sheet including ICD–10 diagnoses and subjective rating.

(b) Rate each in order from item 1 to 18.

(c) Do not include information rated in an earlier item.

(d) Rate the person over the previous 4 weeks.

(e) Rate the most severe problem that has occurred during the period rated.

(f) All items follow the five-point rating format similar to other HoNOS instruments:
0=no problem during the period rated;
1=mild problem;
2=moderate problem;
3=severe problem;
4=very severe problem.

Rate 9 if unknown

I. Behavioural problems (directed at others)

Include behaviour that is directed to other persons. Do not include behaviour that is directed towards self (Scale 2) or primarily at property or other behaviours (Scale 3). Rate risk as it is currently perceived.

0= No behavioural problems directed to others during the period rated.

1= Irritable, quarrelsome, occasional verbal abuse.

2= Frequent verbal abuse, verbal threats, occasional aggressive gestures, pushing or pestering (harassment).

3= Risk, or occurrence of, physical aggression resulting in injury to others requiring simple first aid, or requiring close monitoring for prevention.

4= Risk, or occurrence of, physical aggression producing injury to others serious enough to need casualty treatment and requiring constant supervision or physical intervention for prevention (e.g. restraint, medication or removal).

2. Behavioural problems directed towards self (self-injury)

Include all forms of self-injurious behaviour. Do not include behaviour directed towards others (Scale 1), or behaviour primarily directed at property, or other behaviours (Scale 3).

0= No self-injurious behaviour during the period rated.

1= Occasional self-injurious behaviour (e.g. face-tapping); occasional fleeting thoughts of suicide.

2= Frequent self-injurious behaviour not resulting in tissue damage (e.g. redness, soreness, wrist-scratching).

3= Risk or occurrence of self-injurious behaviour resulting in reversible tissue damage and no loss of function (e.g. cuts, bruises, hair loss).

4= Risk or occurrence of self-injurious behaviour resulting in irreversible tissue damage and permanent loss of functions (e.g. limb contractures, impairment of vision, permanent facial scarring) or attempted suicide.

3. Other mental and behavioural problems

This is a global rating to include behavioural problems not described in Scales 1 or 2. Do not include behaviour directed towards others (Scale 1), or self-injurious behaviour (Scale 2). Rate the most prominent behaviours present. Include: A, behaviour destructive to property; B, problems with personal behaviours, for example, spitting, smearing, eating rubbish, self-induced vomiting, continuous eating or drinking, hoarding rubbish, inappropriate sexual behaviour; C, rocking, stereotyped and ritualistic behaviour; D, anxiety, phobias, obsessive or compulsive behaviour; E, others.

0= No behavioural problem(s) during the period rated.

1= Occasional behavioural problem(s) that are out of the ordinary or socially unacceptable.

2= Behaviour(s) sufficiently frequent and severe to produce some disruption of and impact on own or other people's functioning.

3= Behaviour(s) sufficiently frequent and severe to produce significant disruption and impact on own or other people's functioning, requiring close monitoring for prevention.

4= Constant, severe problem behaviour(s) producing major disruption of and impact on functioning requiring constant supervision or physical intervention for prevention.

4. Attention and concentration

Include problems that may arise from underactivity, overactive behaviour, restlessness, fidgeting or inattention, hyperkinesis or arising from drugs.

0= Can sustain attention and concentration in activities/programmes independently during the period rated.

1= Can sustain attention and concentration in activities/programmes with occasional prompting and supervision.

2= Can sustain attention and concentration in activities/programmes with regular prompting and supervision.

3= Can sustain attention and concentration in activities/programmes briefly with constant prompting and supervision.

4= Cannot participate in activities and programmes even with constant prompting and supervision.

5. Memory and orientation

Include recent memory loss and worsening of orientation for time, place and person in addition to previous difficulties.

0= Can reliably find their way around familiar surroundings and relate to familiar people.

1= Mostly familiar with environment/ person, but with some difficulty in finding their way.

2= Can relate to environment/person with occasional support and supervision.

[†]See pp. 61–66, this issue.

3= Can relate to environment/person with regular support and supervision.

4= Not apparently able to recognise or relate to people and environments.

6. Communication (problems with understanding)

Include all types of responses to verbal, gestural and signed communication, supported if necessary with environmental cues.

0= Able to understand first language (mother tongue) about personal needs and experience during the period rated.

1= Able to understand groups of words/ short phrases/signed communication about most needs.

2= Able to understand some signs, gestures and single words about basic needs and simple commands (food, drink, come, go, sit, etc.).

3= Able to acknowledge and recognise attempts at communication with little specific understanding (pattern of response is not determined by nature of communication).

4= No apparent understanding or response to communication.

7. Communication (problems with expression)

Include all attempts to make needs known and communicate with others (words, gestures, signs). Rate behaviour under Scales 1, 2 and 3.

0= Able to express needs and experience during the period rated.

1= Able to express needs to familiar people.

2= Able to express basic needs only (food, drink, toilet, etc.).

3= Able to express presence of needs, but cannot specify (e.g. cries or screams when hungry, thirsty or uncomfortable).

4= Unable to express need or presence of need.

8. Problems associated with hallucinations and delusions

Include hallucinations and delusions irrespective of diagnosis. Include all manifestations suggestive of hallucinations and delusions (responding to abnormal experiences, e.g. invisible voices when alone).

0= No evidence of hallucinations or delusions during period rated.

1= Occasional odd or eccentric beliefs or behaviours suggestive of hallucinations or delusions.

2= Manifestations of hallucinations or delusions with some distress or disturbance.

3= Manifestations of hallucinations or delusions with significant distress or disturbance.

4= Mental state and behaviour are seriously and adversely affected by hallucinations or delusions with severe distress or disturbance.

9. Problems associated with mood changes

Include problems associated with low mood states, elated mood states, mixed moods and mood swings (alternating between unhappiness, weeping and withdrawal on one hand and excitability and irritability on the other).

0= No evidence of mood change during period rated.

1= Mood present but with little impact (e.g. gloom).

2= Mood change producing significant impact on self or others (e.g. weeping spells, decrease in skills, withdrawal and loss of interest).

3= Mood change producing major impact on self or others (e.g. severe apathy and unresponsiveness, severe agitation and restlessness).

4= Depression, hypomania or mood swings producing severe impact on self and others (e.g. severe weight loss from anorexia or overactivity, agitation too severe to allow time to be engaged in meaningful activity).

10. Problems with sleeping

Do not rate intensity of behaviour disturbance – this should be included in Scale 3. Include daytime drowsiness, duration of sleep, frequency of waking and diurnal variation of sleep pattern.

0= No problem during the period rated.

1= Occasional mild sleep disturbance with occasional waking.

2= Moderate sleep disturbance with frequent waking, or some daytime drowsiness.

3= Severe sleep disturbance or marked daytime drowsiness (e.g. restlessness/ overactivity/waking early) on some nights.

4= Very severe sleep disturbance with disturbed behaviour (e.g. restlessness/ overactivity/waking early most nights).

11. Problems with eating and drinking

Include both increase and decrease in weight. Do not rate pica – which should be rated in Scale 3. This scale does not include problems experienced by people who cannot feed themselves (e.g. people with severe physical disability).

0= No problem with appetite during the period rated.

1= Slight alteration to appetite.

2= Severe alteration in appetite with no significant weight change.

3= Severe disturbance with some weight change during the period rated.

4= Very severe disturbance with significant weight change during the period rated.

12. Physical problems

Include illnesses from any cause that adversely affects mobility, self-care, vision and hearing (e.g. dementia, thyroid dysfunction, tremor affecting dexterity). Do not include relatively stable physical disability (e.g. cerebral palsy, hemiplegia). Behavioural disorders caused by physical problems should be rated under Scales 1, 2 and 3 (e.g. constipation producing aggression).

0= No increased incapacity due to physical problems during the period rated.

1= Mildly increased incapacity, for example, viral illness, sprained wrist.

2= Significant incapacity requiring prompting and supervision.

3= Severe incapacity requiring some assistance with basic needs.

4= Total incapacity requiring assistance for most basic needs such as eating and drinking, toileting (fully dependent).

13. Seizures

Include all types of fits (partial, focal, generalised, mixed, etc.) to rate the short-term effect on the individual's daily life. Rate the effects of the fits. Do not include

behavioural problems caused by, or associated with, fits (use Scales 1, 2 and 3).

0= **No increased incapacity due to physical problems** during the period rated.

1= **Occasional seizures** with minimal immediate impact on daily activities (e.g. resumes after seizures).

2= **Seizures of sufficient frequency or severity** to produce a significant immediate impact on daily activities (e.g. resumes activity after a few hours).

3= **Seizures of sufficient frequency or severity** producing a severe immediate impact on daily activities requiring simple first aid for injuries etc. (e.g. resumes activities next day).

4= **Frequent poorly controlled seizures** (may be accompanied by episodes of status epilepticus) requiring urgent clinical attention.

14. Activities of daily living at home

Include such skills as cooking, cleaning and other household tasks. **Do not rate problems with daily living outside the home** (Scale 15). **Do not rate problems with self-care** (Scale 16). Rate what is seen regardless of cause, for example, disability, motivation etc. Rate performance not potential. Rate the current level achieved with the existing support.

0= **Performs or contributes towards activities** of daily living at home.

1= **Some limitations** in performing or contributing towards household tasks.

2= **Significant limitations** in performing or contributing towards household tasks (e.g. failure to wash or tidy up, difficulty in preparing meals).

3= **Major limitations** in performing or contributing towards household tasks (e.g. home neglected, dirty, untidy; no domestic routine).

4= **Gross neglect or danger** resulting from no apparent contribution to daily living activities.

15. Activities of daily living outside the home

Include skills such as budgeting, shopping, mobility and the use of transport, etc. **Do not include problems with activities of daily living at home** (Scale 14). Do not rate

problems with self-care (Scale 16). Rate the current level with the existing support.

0= **Regular use of facilities and public amenities** (e.g. shopping).

1= **Some limitation in activity** (e.g. difficulty with the use of public amenities or transport).

2= **Significant limitations of activity** relating to any one of: shopping, use of transport, public amenities.

3= **Major restrictions in activity** relating to more than any one of: shopping, use of transport, public amenities.

4= **Severe restrictions in the use of shops,** transport, facilities, etc.

16. Level of self-care

Rate the overall level of functioning in activities of self-care such as eating, washing, dressing and toileting. Rate current level achieved with the existing support. Rate appearance not motivation.

0= **Appearance and personal hygiene maintained.**

1= **Some deficits in personal appearance, personal hygiene** or attention to health (e.g. poor grooming).

2= **Significant deficits in personal appearance, personal hygiene** or attention to health causing a problem with social acceptability, but not sufficient to pose a health risk (e.g. body odour, unkempt hair or nails).

3= **Major deficits in personal appearance, personal hygiene** or attention to health posing a health risk (e.g. skin rashes, gum infection, not fully dressed).

4= **Gross self-neglect with severe difficulties** relating to appearance, hygiene and diet posing a major health risk (e.g. pressure sores).

17. Problems with relationships

Include effects of problems with relationships with family, friends and carers (in residential and day/leisure settings). Measure what is occurring regardless of cause, for example, somebody who is known to have good relationships may still display problems.

0= **Positive and frequent contact with family** or friend or carers.

1= **Generally positive relationships,** but some strain or limitations in contact.

2= **Some positive relationships,** but current disruptions of contact or worsening of relationships.

3= **Difficulties in relationships** with risk of breakdown or infrequent contact.

4= **Significant relationships broken down** with no current contact.

18. Occupation and activities

Rate the overall level of problems with quality of daytime environment. Take account of frequency and appropriateness of, and engagement with, daytime activities. Consider factors such as lack of qualified staff, equipment and appropriateness with regard to age and clinical condition. Do not rate problems with self-care (Scale 16).

0= **Fully engaged with acceptable range of activities.**

1= **Uses reasonable range of activities,** but some limitation of access or appropriateness.

2= **Uses limited range of activities,** limited availability or appropriateness.

3= **Attends daytime activity irregularly.**

4= **No engagement with daytime activity.**

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APPENDIX

HoNOS–LD score sheet

Scale 0–4   *Rate 9 if not known*

1. Behavioural problems ☐
    (directed at others)
2. Behavioural problems directed towards ☐
    self (self-injury)
3. Other mental and behavioural ☐
    problems (specify problem, A, B, C, D
    or E)

4. Attention and concentration ☐
5. Memory and orientation ☐
6. Communication (problems with ☐
    understanding)
7. Communication ☐
    (problems with expression)
8. Problems associated with ☐
    hallucinations and delusions
9. Problems associated with ☐
    mood changes
10. Problems with sleeping ☐

11. Problems with eating and drinking ☐
12. Physical problems ☐
13. Seizures ☐
14. Activities of daily living at home ☐
15. Activities of daily living outside the home ☐
16. Level of self-care ☐
17. Problems with relationships ☐
18 Occupation and activities ☐

Total score ☐
Subjective score ☐

Appendix J
Reiss Screen for Maladaptive Behaviors (RSMB)

Reiss Screen for Maladaptive Behaviour

Behaviour

Version 1.1

INSTRUCTIONS

The Reiss Screen for Maladaptive Behaviour was designed for use with adolescents and adults who are mentally retarded. The subject should be at least 12 years of age. The scale is completed by caretakers, teachers, service providers, or other professionals who know the subject reasonably well. The scale takes about 20 minutes to complete.

The test booklet presents a list of maladaptive behaviours that could create problems in the lives of mentally retarded adolescents and adults. Your task is to report which of these behaviours, if any, seem to present problems for the person being evaluated.

Each behaviour category is briefly defined in plain language. A few examples of each category are given. The examples are presented to help you understand the meaning of the definition. Only rarely will a person show all of the examples listed for a category. More typically, a person will show only one or none of the examples. If a person shows none of the examples listed for a specific category, you still need to evaluate whether that category is no problem, a problem, or a major problem for that person. There are many behaviours that fit the category but are not listed as examples.

Read each definition carefully; study the examples to help you understand the category, and ask yourself, "Is this behaviour currently (No Problem, a Problem, or a Major Problem) in the life of the person being evaluated?"

RATING SCALE

No Problem. Use this rating if any of the following are true:
1. The behaviour category does not apply to the person you are rating. For example, the category of "lying'', does not apply to a person who is non-verbal.
2. The person you are evaluating does not engage in the behaviour.
3. The behaviour does not occur with sufficient frequency, intensity, or severity to be considered a current problem in the life of the person you are evaluating.

Problem. Use this rating if one or more of the following are true:
1. The behaviour causes a significant degree of discomfort and/or suffering for the person being evaluated.
2. The behaviour interferes with the person's social functioning.
3. The behaviour interferes with the person's vocational functioning.
4. The behaviour occurs often or with an unusual degree of severity.

Major Problem. Use this rating if one or more of the following are true:

1. The behaviour causes a great deal of discomfort and/or suffering for the person you are evaluating.
2. The behaviour occurs with a very high frequency or intensity.
3. The behaviour significantly interferes with the person's vocational or social adjustment.
4. The behaviour causes placement in a restrictive environment or increases the need for supervision.

Examples: *Sadness* is "no problem" when it occurs occasionally or is a temporary reaction to a bad day or a minor problem; sadness is a "problem" when it occurs often; sadness is a "major problem" when it is so severe that it interferes significantly with the person's friendships, everyday activities, or the ability to function. *Aggression* is "no problem" when it occurs rarely and in response to provocation; aggression is a "problem" when it leads to frequent fights or causes others to dislike the person; aggression is a "major problem" when it causes loss of employment or influences residential or educational placements.

Respond by Circling Desired Alternative

1. AGGRESSIVE Attacks or threatens others; the attacks may be physical or verbal in nature. *Examples: fighting, violent acts, hitting, insulting.*

   No Problem   Problem   Major Problem

2. ANXIOUS Feels nervous or tense. *Examples: nervous, panicky; trembly (shaky), apprehensive, worried.*

   No Problem   Problem   Major Problem

3. ATTENTION-SEEKING Tries to gain the attention of others in excessive or inappropriate ways. *Examples: approaches people repeatedly within a short time-span, repeatedly seeks approval, dramatic behaviour, flamboyant.*

   No Problem   Problem   Major Problem

4. BODY STRESS Complains about aches and pains. *Examples: headaches, stomach aches dizziness, constipation, diarrhoea.*

   No Problem   Problem   Major Problem

5. COMPLAINING Has an overly critical, negative attitude and tends to find fault with others or with situations; *Examples: finds fault with job, rules, or co-workers.*

No Problem   Problem   Major Problem

6. CONFUSED THINKING Disconnected (poorly related) ideas or thoughts. *Examples: thoughts are hard to follow, thoughts jump from one topic to another, disoriented as to time or place.*

No Problem   Problem   Major Problem

7. CRYING SPELLS Periodic bouts of uncontrollable sobbing. *Examples: quickly or easily moved to tears cries over minor annoyances.*

No Problem   Problem   Major Problem

8. DELUSIONS Firmly held beliefs that are not based on reality. *Examples: believes that others are out to get him/her, believes that he/she is in contact with the devil, believes that he/she is somebody else.*

No Problem   Problem   Major Problem

9. DEPENDENT An excessive reliance on others. *Examples: seeks help to an excessive degree, excessive advice seeking, excessive need for companionship*

No Problem   Problem   Major Problem

10. DESTRUCTIVE Deliberately damages property. *Examples: breaks windows, tears books/papers, vandalism.*

No Problem   Problem   Major Problem

11. DRUG/ALCOHOL ABUSE Excessive drinking or excessive use of drugs. *Examples: drunkenness, uses cocaine, heroin addict.* (Do not include cigarette smoking or coffee drinking).

   No Problem   Problem   Major Problem

12. EATING PROBLEM The person is gaining or losing weight. *Examples: overeats, poor appetite.*

   No Problem   Problem   Major Problem

13. ECHOLALIA Usually repeats what others say to him/her. *Examples: when you say "How are you doing today, Joan"; Joan says "How are you doing today, Joan", when you say "I like ice cream"; he/she says "I like ice cream.*

   No Problem   Problem   Major Problem

14'. EUPHORIA Has sudden bursts of energy that may last for periods of a couple months. *Examples: has periods of excitement, excessively cheerful, too much laughter, excessively optimistic, rapid speech, ideas race from one topic to another.*

   No Problem   Problem   Major Problem

15. FEARFUL Is afraid of something to the extent that everyday functioning is affected. *Examples: afraid to go places, afraid to try new activities, afraid of many different things.*

   No Problem   Problem   Major Problem

16. HALLUCINATIONS Experiences things that are not really there. *Examples: hears voices, hears sounds, has visions, strange bodily sensations.*

   No Problem   Problem   Major Problem

17. HOSTILE Experiences anger and/or expresses anger in ways that are inappropriate for the situation. Examples: gets mad easily, argues a lot with others.

No Problem   Problem   Major Problem

18. IMPULSIVE Acts without thinking. Examples: demands must be met immediately, reacts without considering consequences of behaviour.

No Problem   Problem   Major Problem

19. INATTENTIVE Pays little attention to people or to events around him/her. Examples: pays little attention when spoken to, "spaced out," preoccupied.

No Problem   Problem   Major Problem

20. LOW ENERGY Lacks energy for everyday activities. Examples: too tired to participate in everyday events, moves slow fy, lacks initiative.

No Problem   Problem   Major Problem

21. NONASSERTIVE Fails to express preferences and opinions. Examples: lets others make decisions, doesn't ask for help or information, gives into demands, lets others take advantage.

No Problem   Problem   Major Problem

22. OBJECT ATTACHMENT Strong and persistent attachment to a particular object. *Examples: often wants to hold a ball; likes to carry around a key chain and gets upset when the key chain cannot be found.*

No Problem   Problem   Major Problem

23. OVERACTIVE Excessive movement to the point where the person has difficulty staying still. *Examples: appears to be in constant motion, excessive physical movement.*

No Problem   Problem   Major Problem

24. OVERLY SENSITIVE Excessive or inappropriate reactions to criticism. *Examples: reacts to failure by crying, withdraws when criticised, quits easily.*

No Problem   Problem   Major Problem

25. PARANOIA Excessive mistrust and suspicion of others. *Examples: quick to assume that others have bad intentions, tends to blame others for own faults, thinks that he/she is treated unfairly.*

No Problem   Problem   Major Problem

26. REGRESSIVE BEHAVIOUR A noticeable deterioration in everyday self-care skills. *Examples: a person who used to bathe now neglects to do so; deteriorated personal habits; unkempt . or unshaven appearance (when this represents a deterioration of behaviour).*

No Problem   Problem   Major Problem

27. SADNESS Feelings of unhappiness that last for significant periods of time. *Examples: fails to adjust to death, rejection, or a significant loss.*

No Problem   Problem   Major Problem

28. SELF-INJURY Repeatedly injures body on purpose. *Examples: bites arm, hits self repeatedly, repeated head-banging.*

No Problem   Problem   Major Problem

29. SELF-STIMULATORY BEHAVIOUR Repetitive movements that are performed frequently and appear to be non-functional. *Examples: body-rocking, object twirling, head-rocking.*

No Problem   Problem   Major Problem

30. SEXUAL PROBLEM Either a disturbance of sexual functioning or repeated efforts to perform sexual acts that are socially disapproved. *Examples: makes inappropriate sexual advances; masturbates in public; marital problem related to sex.*

No Problem   Problem   Major Problem

31. SLEEP PROBLEM A disturbance of usual sleeping patterns. *Examples: does not get enough sleep, sleeps too much, has trouble falling asleep, and wakes up too early.*

No Problem   Problem   Major Problem

32. SOCIAL INADEQUACIES Has difficulty relating to peers in appropriate or satisfying ways. *Examples: has no friends, tends to be disliked, insensitive to the feelings of other people.*

No Problem   Problem   Major Problem

33. STEALING Takes property that belongs to others. *Examples: takes roommate's possessions, shoplifting, purse snatching.*

No Problem   Problem   Major Problem

34. SUICIDAL TENDENCIES. Seriously thinks about killing himself/herself. *Examples: says that he/she would like to die, threatens to take an overdose of pills, cuts own wrists, tries to get run over by cars.*

No Problem   Problem   Major Problem

35. TEMPER / TANTRUMS Angry outbursts when frustrated or disappointed. *Examples: shouts and yells when not given in to, has outbursts when asked to do something he/she does not want to do.*

    No Problem   Problem   Major Problem

36. TIREDNESS Lacks motivation to perform every day activities. Examples: listless, inactive, easily fatigued.

    No Problem   Problem   Major Problem

37. UNUSUAL MOTOR MOVEMENTS Repetitive movements beyond the control of the person. Examples: blinks a lot, strange motor movements, frequent shrugs, hand flapping, grunts a lot.

    No Problem   Problem   Major Problem

38. WITHDRAWN Avoids personal contact with other people. Examples: excessively shy, doesn't participate in group activities, prefers to be alone, socially isolated.

    No Problem   Problem   Major Problem

Reiss Screen

Name _____

Facility _____

Sex _____ Age _____ Race _____ Date _____ Rater - 1 _____ Rater - 2 _____

Scored by _____

Scales

Scales	Raw Scores	Scales	Raw Scores
Aggressive		Depression (B)	
Autism		Depression (P)	
Psychosis		Dependent PD	
Paranoia		Avoidant	

Other Maladaptive Behaviour

Drug Abuse		Sexual Problem	
Overactive		Stealing	
Self-Injury		Suicidal	

26-Item Total Score =

26-Item Total Score

	Rater-1	Rater-2	Average	Raw Score
1.Aggressive				
2.Anxious				
3.Attention-Seeking				
4.Body Stress				
5.Complaining				
6.Confused Thinking				
7. Crying Spells				
8.Delusions				
9.Dependent				
10.Destructive				
12.Eating Problem				
15.Fearful				
16.Hallucinations				
17.Hostile				
18.Impulsive				
19.Inattentive				
20.Low Energy				
21.Nonassertive				
24. Sensitive				
25.Paranoia				
26.Regressive				
27.Sadness				
31.Sleep Problem				
32.Social inadequacies				
35. Tantrums				
38.Withdrawn				

	Rater-1	Rater-2	Average	Raw Score
Aggressive Behaviour				
1.Aggressive				
10 Destructive				
17.Hostile				
18.Impulsive				
35.Temper Tantrums				
Sum of Averages =				

	Rater-1	Rater-2	Average	Raw Score
Autism				
13.Echolalia				
22.Object Attachment				
29Self-Stim. Behaviour:				
37.Unusual Movements				
38.Withdrawn				
Sum of Averages =				

	Rater-1	Rater-2	Average	Raw Score
Psychosis				
6.Conf&sed Thinking				
8.Delusions.				
16.Hallucinations				
25.Paranoia				
32.Social inadequacies				
Sum of Averages =				

	Rater-1	Rater-2	Average	Raw Score
Paranoia				
5.Complaining				
16.Hallucinations				
17.Hostile				
24.Sensitive				
25.Paranoia				
Sum of Averages =				

Depression (B)

	Rater-1	Rater-2	Average	Raw Score
2.Anxious				
7.Crying Spells				
15.Fearful				
24.Sensitive				
27.Sadness				
Sum of Averages =				

Depression (P)

	Rater-1	Rater-2	Average	Raw Score
4.Body Stress				
12.Eating Problem				
20.Low Energy				
26.Regressive Behaviour.				
31.Sleep Problem				
Sum of Averages =				

Dependent PD

	Rater-1	Rater-2	Average	Raw Score
2.Anxious				
3.Attention-Seeking				
4.Body Stress				
5.Complaining				
9.Dependent				
Sum of Averages =				

Avoidant

	Rater-1	Rater-2	Average	Raw Score
19.Inattentive				
20.Low Energy				
21.Nonassertive				
32.Social Inadequacies.				
38.Withdrawn				
Sum of Averages =				

	Rater-1	Rater-2	Average	Raw Score
Other Maladaptive Behaviour				
11.Drug Abuse				
23.Overactive				
28.Self-Injury				
30.Sexual Problem				
33.Stealing				
34.Suicidal				
Sum of Averages =				
Experimental Items	Rater-1	Rater-2	Average	Raw Score
14.Euphoria				
36.Tiredness				
Sum of Averages =				

Appendix K
Behavior Problems Inventory- Short Form (BPI-S)

BPI-idd [DRAFT]

The Behavior Problems Inventory for Individuals with Intellectual Disabilities

The Target Individual:

ID (please leave blank):

Age: ____ years ____ months; Gender: □ male □ female

Ethnicity/Race:

Intellectual Disability:

□ no ID; □ unknown;

□ mild (IQ 56-70); □ moderate (IQ 41-55); □ severe (26-40); □ profound (< 26)

The Respondent

Relationship to the individual: ____

Time you typically spent with the individual per day: ____

How long have you known the individual: ____

Instructions

On the following pages you will find broad definitions followed by specific descriptions of three types of behavior problems: self-injurious behaviors (items 1-8), stereotyped behaviors (items 9-20), and aggressive/destructive behaviors (items 21-30). Please indicate which behaviors you have observed in this individual *during the past six months* by circling the number in the appropriate boxes (1) how often a described behavior typically occurs and (2) how serious a problem the behavior is. If the behavior has never been observed during the last six months, or if it poses no problem, check "never" (i.e., number "0"). For each item, please multiply the scores and put the product in the far right column. For subscale total scores, add the product sum.

SELF-INJURIOUS BEHAVIOR

Self-injurious behavior (SIB) causes damage to the person's own body, i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.

	Never or no problem	Average frequency of occurrence							Severity of the Problem			Multiply the frequency and the severity scores
		Fewer than once a month	About once per month	About once per week	About once per day	About once per hour	More than once per hour	Once per minute or more	Mild	Moderate	Severe	
1	Self-biting	0	1	2	3	4	5	6	7	1	3	9	
2	Head hitting with hand or other body part	0	1	2	3	4	5	6	7	1	3	9	
3	Body hitting (except for the head) with own hand or with any other body part	0	1	2	3	4	5	6	7	1	3	9	
4	Self-scratching	0	1	2	3	4	5	6	7	1	3	9	
5	Pica	0	1	2	3	4	5	6	7	1	3	9	
6	Inserting inappropriate objects in nose, ears, anus, etc.)	0	1	2	3	4	5	6	7	1	3	9	
7	Hair pulling (tearing out patches of hair)	0	1	2	3	4	5	6	7	1	3	9	
8	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	5	6	7	1	3	9	
												Subtotal:	

STEREOTYPED BEHAVIOR

BPI-idd [DRAFT]

The Behavior Problems Inventory for Individuals with Intellectual Disabilities

The Target Individual:
ID (please leave blank):
Age: ___ years ___ months; Gender: □ male □ female
Ethnicity/Race:
Intellectual Disability:
□ no ID; □ unknown;
□ mild (IQ 56-70); □ moderate (IQ 41-55); □ severe (26-40); □ profound (<26)

The Respondent
Relationship to the individual:
Time you typically spent with the individual per day:
How long have you known the individual:

Instructions
On the following pages you will find broad definitions followed by specific descriptions of three types of behavior problems: self-injurious behaviors (items 1-8), stereotyped behaviors (items 9-20), and aggressive/destructive behaviors (items 21-30). Please indicate which behaviors you have observed in this individual *during the past six months* by circling the number in the appropriate boxes (1) how often a described behavior typically occurs and (2) how serious a problem the behavior is. If the behavior has never been observed during the last six months, or of it poses no problem, check "never" (i.e., number "0"). For each item, please multiply the scores and put the product in the far right column. For subscale total scores, add the product sum.

SELF-INJURIOUS BEHAVIOR

Self-injurious behavior (SIB) causes damage to the person's own body, i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.

	Never or no problem	Average frequency of occurrence							Severity of the Problem			Multiply the frequency and the severity scores
		Fewer than once a month	About once per month	About once per week	About once per day	About once per hour	More than once per hour	Once per minute or more	Mild	Moderate	Severe	
1	Self-biting	0	1	2	3	4	5	6	7	1	3	9	
2	Head hitting with hand or other body part	0	1	2	3	4	5	6	7	1	3	9	
3	Body hitting (except for the head) with own hand or with any other body part	0	1	2	3	4	5	6	7	1	3	9	
4	Self-scratching	0	1	2	3	4	5	6	7	1	3	9	
5	Pica	0	1	2	3	4	5	6	7	1	3	9	
6	Inserting inappropriate objects in nose, ears, anus, etc.)	0	1	2	3	4	5	6	7	1	3	9	
7	Hair pulling (tearing out patches of hair)	0	1	2	3	4	5	6	7	1	3	9	
8	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	5	6	7	1	3	9	
												Subtotal:	

STEREOTYPED BEHAVIOR

A

Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.

		Never	Fewer than once a month	About once per month	About once per week	About once per day	About once per hour	More than once per hour	Once per minute or more	Mild	Moderate	Severe	Multiply the frequency and the severity scores
9	Rocking back and forth, repetitive body movements	0	1	2	3	4	5	6	7	1	3	9	
10	Sniffing objects, own body	0	1	2	3	4	5	6	7	1	3	9	
11	Waving or shaking arms	0	1	2	3	4	5	6	7	1	3	9	
12	Manipulating (e.g., twirling, spinning) objects repeatedly	0	1	2	3	4	5	6	7	1	3	9	
13	Repetitive hand and/or finger movements	0	1	2	3	4	5	6	7	1	3	9	
14	Yelling and screaming	0	1	2	3	4	5	6	7	1	3	9	
15	Pacing, jumping, bouncing, running	0	1	2	3	4	5	6	7	1	3	9	
16	Rubbing self	0	1	2	3	4	5	6	7	1	3	9	
17	Gazing at hands or objects	0	1	2	3	4	5	6	7	1	3	9	
18	Bizarre body postures	0	1	2	3	4	5	6	7	1	3	9	
19	Clapping hands	0	1	2	3	4	5	6	7	1	3	9	
20	Grimacing	0	1	2	3	4	5	6	7	1	3	9	
												Subtotal:	

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

Aggressive or destructive behaviors are offensive actions or deliberate over attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person.

		Never	Fewer than once a month	About once per month	About once per week	About once per day	About once per hour	More than once per hour	Once per minute or more	Mild	Moderate	Severe	Multiply the frequency and the severity scores
21	Hitting others	0	1	2	3	4	5	6	7	1	3	9	
22	Kicking others	0	1	2	3	4	5	6	7	1	3	9	
23	Pushing others	0	1	2	3	4	5	6	7	1	3	9	
24	Biting others	0	1	2	3	4	5	6	7	1	3	9	
25	Grabbing and pulling others	0	1	2	3	4	5	6	7	1	3	9	
26	Scratching others	0	1	2	3	4	5	6	7	1	3	9	
27	Pinching others	0	1	2	3	4	5	6	7	1	3	9	
28	Verbally abusive with others	0	1	2	3	4	5	6	7	1	3	9	
29	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	5	6	7	1	3	9	
30	Bullying - being mean or cruel (e.g., grabbing toys or food from others)	0	1	2	3	4	5	6	7	1	3	9	
												Subtotal:	

Appendix L
Health Census: Information Sheet- Participants with Intellectual Disabilities

Participant Information Sheet

What we want to know?

We would like to find out about your health and some of the health problems you may have.

MHC have a file about you. This file has things like what tablets you take and what health problems you have in it.

We would like your permission to use some information from your file, to see what health problems you have and to see if they are similar to what other people have.

What will happen?

1. We will ask you for your permission

2. We will collect information from your file about your health.

3. We will put the information on to a computer with a password, but we won't use your name, age or address.

4. If you agree, we will look to see if lots of people have the same kinds of health problems.

5. We will use the information to help us understand more about your health

6. This will help MHC to see what kind of help you and the people you live with might need to be more healthy.

Can I say no?

- It's OK to say no if you want to.
- You can say no now, or if you change your mind later.
- You can tell us, or a member of staff at any time.

Questions?

- You can ask us anything you want now.
- Or, you can ask a member of staff to phone us.

Taflen Gwybodaeth Cyfrannogwyr

Beth rydym eisiau gwybod?

Rydym eisiau gwybod pethau am eich iechyd ag am rhai o'r problemau iechyd rydych yn cael.

Mae gan MHC ffeil amdanoch. Mae gan y ffeil gwybodaeth fel pa dabledi rydych yn cymryd, a pha afiechydon sydd gennych.

Rydym eisiau eich caniatâd i ddefnyddio'r wybodaeth yma o'ch ffeil, i weld pa broblemau iechyd sydd ganddo'ch ac i weld os maent yn debyg i rai pobl eraill.

Beth fydd yn digwydd?

1. Fe wnawn ni ofyn am eich caniatâd

2. Fe wnawn ni casglu data o'ch ffeil am eich iechyd

3. Fe wnawn ni rhoi'r data yma ar gyfrifiadur gyda chyfrinair i gadw'n ddiogel. Ni wnawn ni defnyddio eich enw, oedran na chyfeiriad.

4. Os wnewch chi gytuno , fe wnawn ni edrych i weld os oes gan nifer o bobl yr un mathau o broblemau iechyd

5. Fe wnawn ni defnyddio'r wybodaeth i'n helpu ni deall mwy am eich iechyd

6. Fe wneith hyn helpu MHC i weld pa fath o help yr ydych chi a'r bobl rydych yn byw gydag i gael fod yn fwy iach.

Fedrai dweud na?

- Mae'n iawn i ddweud na os rydych eisiau
- Fedrwch chi ddweud na nawr, neu medrwch chi newid eich meddwl wedyn
- Fedrwch chi ddweud wrthym ni, neu aelod o staff

Cwestiynnau?

- Fedrwch chi ofyn unrhyw beth wrthym ni nawr
- Neu medrwch chi ofyn i aelod o staff i'n ffonio

Appendix M
Health Census: Information Sheet- Staff

Study Information Sheet

Purpose of Study

The aims of this study are to describe the physical health, mental health and behavioural problems of adults with Intellectual Disabilities (ID) living in hospital, residential and community services. The research will also explore the relationships between physical health problems, mental health and behavioural problems and ability levels of adults with an ID. The research also aims to assess the levels of physical activity/exercise in adults with ID and to see if this is related to physical and mental health. This information may be used to inform the future care of adults with intellectual disabilities.

What will be involved?

Assessments are routinely completed, by suitably trained and qualified staff, on all clients in MHC services using a variety of different measures, to assess a client's physical health, mental health, abilities and difficulties. We will be collecting the information from 6 of these measures for all clients with ID in MHC services. In addition, 1 new measure will be added and will be completed, by suitably trained and qualified MHC staff. This information from each client will be collected and entered onto a secure database. Once complete, this database will identify the physical and mental health needs of each client at MHC. In order to protect anonymity, we will remove the names, dates of birth and addresses of each client. We would like to ask each client if they would kindly allow this anonymous information to be used to inform other people of the findings. These findings may then be used to help improve the physical and mental health care of adults with an intellectual disability. The

process for obtaining consent from clients for us to use their information in this way is

shown on the next page.

<u>Flow Chart of the Capacity & Consent Process</u>

Functional Assessment of Capacity to give Consent to Participate in Research

Study

Individual has Capacity?

     Yes   No

  Obtain Informed Consent   Complete Best Interests Checklist

                                    & Arrange Best Interests Meeting

 Yes   No

                                     Research in Client's

                                     Best Interests?

Continue Research   No not include

with client   client in research   Yes   No

Consent withdrawn   Obtain Proxy   Do not include

at a later date   consent   client in research

Yes   No

Do not include   Include client

client in research   in research

Confidentiality & Data Protection

All data from clients will be anonymous. Data entered into the database will be password protected. All paperwork relating to capacity and informed consent will be locked in a filing cabinet in the School of Psychology, Bangor University. Only researchers directly involved in the project will have access to the information.

At the end of the study

The overall findings of the research will be summarised and circulated to all clients and staff automatically. The results from the research may be published, again to inform wider understanding.

Any questions?

If you have any questions regarding this research, please contact, Prof Oliver Turnbull, the School of Psychology, Bangor University, Pen yr Allt Road, Bangor, Gwynedd, LL57 2AS. Or alternatively phone 01248 388656 during normal office hours, or email the researchers (see below).

Ceri Jones   Cara Rogowski

c.c.jones@bangor.ac.uk   psp80f@bangor.ac.uk

Supervised by:

Professor Richard Hastings, School of Psychology, Bangor University

Dr Carl Hughes, School of Psychology, Bangor University

Deborah Roberts, Clinical Lead & Consultant Clinical Psychologist, MHC

Taflen Gwybodaeth

Pwrpas yr Ymchwil

Pwrpas yr ymchwil yma yw disgrifio broblemau iechyd corfforol, iechyd meddwl a phroblemau ymddygiadol oedolion ag anableddau dysgu (AD) sydd yn byw mewn ysbytai a gwasanaethau preswyl a chymunedol. Bydd yr ymchwil hefyd yn darganfod y perthnasau rhwng problemau iechyd corfforol, iechyd meddwl a phroblemau ymddygiadol oedolion ag AD. Bwriadir yr ymchwil hefyd i asesu lefelau ymarfer corf oedolion ag AG i weld os bod yna perthynas rhyngddo ag iechyd corfforol a feddyliol.

Beth fydd yn digwydd?

Mae asesiadau yn cael ei gwblhau yn aml, fel mater o drefn yn MHC gan aelodau o staff sydd wedi'u hyfforddi. Defnyddir y rhain i asesu iechyd corfforol, iechyd meddyliol, medrau ag anawsterau cleientiaid. Mi fyddwn yn casglu gwybodaeth o 6 o'r mesuriadau yma ar gyfer yr holl gleientiaid ag AD yn MHC. Yn ogystal, mi fyddwn yn ychwanegu 1 mesur a bydd yn cael ei gwblhau gan staff a bydd wedi'u hyfforddi. Bydd yr holl wybodaeth yma yn cael eu casglu ac yn cael ei ychwanegu i gronfa ddata diogel. Pan wedi'i gwblhau, mi fydd y gronfa ddata yma yn gallu adnabod anghenion iechyd corfforol a meddyliol cleientiaid MHC sydd ag AD. Er mwyn sicrhau anhysbysrwydd, mi fyddwn yn dileu enwau, dyddiau geni a chyfeiriadau pob cleient. Rydym eisiau gofyn caniatâd pob cleient i ni ddefnyddio'r data anhysbys yma er mwyn hysbysu'r darganfyddiadau i eraill. Gall y darganfyddiadau yma helpu i wella iechyd corfforol a feddyliol oedolion ag AD. Mae'r broses o sicrhau cydsyniad wedi ei amlinellu isod: -

Asesiad gweithredol o gynhwysedd i gydsynio i gymryd rhan mewn ymchwil.

Oes gan y cleient cynhwysedd

Oes   Nag oes

Derbyn cydsyniad gwybodus   Trefnu cyfarfod Pennaf Les

Ie   Na   Ymchwil o bennaf les i'r cleient

Parhau â ymchwil   Peidio a   Ydy   Nac Ydy

                    chynnwys cleient

Diddymir Cydsyniad gwybodus   Derbyn cydsyniad   Peidio a chynnwys

yn y dyfodol   Ddirprwyol   cleient

Ie   Na

Peidio a chynnwys   Cynnwys cleient yn

cleient yn yr   yr ymchwil

ymchwil

Cyfrinachedd a Gwarchod Data

Mi fydd yr holl ddata yn anhysbys. Mi fydd data yn cael ei ychwanegu at gronfa ddata a fydd wedi ei ddiogelu gan gyfrinair. Mi fydd gwaith papur i wneud â chynhwysedd a chydsyniad yn cael ei chloi mewn cwpwrdd ffeilio'r Ysgol Seicoleg, Prifysgol Bangor. Ond pobl yn gysylltiedig â'r ymchwil bydd a'r hawl i'w weld.

Ar ddiwedd yr ymchwil

Mi fydd canlyniadau'r ymchwil yn cael eu crynhoi a'u cylchlythyru i holl cleientiaid a staff MHC. Efallai caiff y canlyniadau eu cyhoeddi er mwyn cynyddu gwybodaeth a dealltwriaeth.

Unrhyw gwestiynau?

Os oes gennych unrhyw gwestiynau ynglŷn â'r ymchwil, yna cysylltwch â Yr Athro Oliver Turnbull, Ysgol Seicoleg, Prifysgol Bangor, Ffordd Pen yr Allt, Bangor, Gwynedd, LL57 2AS. Neu ffoniwch 01248 388656 yn ystod oriau gwaith. Fedrwch hefyd cysylltu â'r ymchwilwyr (gweler isod).

Ceri Jones   Cara Rogowski

c.c.jones@bangor.ac.uk   psp80f@bangor.ac.uk

Gorchwiliwyd gan:

Yr Athro Richard Hastings, Ysgol Seicoleg, Prifysgol Bangor

Dr Carl Hughes, Ysgol Seicoleg, Prifysgol Bangor

Deborah Roberts, Arweinydd Clinigol & Seicolegydd Clinigol, MHC

Appendix N
Health Census: Functional Assessment of Capacity

Mental Capacity Act 2005
Functional Assessment of Capacity
CONFIDENTIAL

Name…………………………..……………………………………………..

DoB……………………...

Preferred Language…………..…………………………………………………

Name of Unit………..……………………….…………………………………

DIAGNSTIC THRESHOLD
Does the patient/resident have an impairment of, or a disturbance in, the functioning
of the mind or brain?   **YES**   **NO**

If **YES** record nature of the disturbance

Neurological DisorderIntellectual disability Mental Disorder
Dementia   Stroke   Head Injury
Delirium   Unconsciousness   Substance Use
Other (give details)

NATURE OF DECISIONS/ACTIONS/INTERVENTIONS PROPOSED
Record below the nature of the decision for the person being assessed

FUNCTIONAL ASSESSMENT
1. Is the patient/resident able to understand the relevant information, for example, the
purpose of the research and the consequences of using data for research purposes?
                                        YES   **NO**
Give details

2. Is the patient/resident able to retain the relevant information (as above)?
                                        YES   **NO**
Give details

3. Is the patient/resident able to use or weigh the relevant information as part of the decision making process (as above)?

YES   **NO**

Give details

4. Is the patient/resident able to communicate the decision(s) verbally or non-verbally (as appropriate)?

YES   **NO**

Give details

Answering no to 1-3 indicates lack of capacity – complete "Best Interests Checklist" and refer decision to "Best Interests Meeting".
Answering no to 4 DOES NOT indicate incapacity – ensure practical measures are used to enable communication, for example liaising with Speech & Language Therapist.

Details of Assessor

Name……………………………………………………………………………

Nature of professional relationship………………………..…………………………

Nature of interest (financial or other) in matter for which assessment was carried out

……………………………………………………………………………………

……………………………………………………………………………………

Signed…………………………………………………………………………

Date & Time………………..……………………………………………………….

Details of Witness

Name……………………………………………………………...………..

Nature of professional relationship……………..…………………………………

Signed…………………………………………………………………………...

Date & Time…………………………………………………………………………

Guidelines for the Functional Assessment of Capacity

Diagnostic Threshold

The Mental Capacity Act (2005) acknowledges that if there is an established diagnosis of mental illness, intellectual disability or some other condition, then this is sufficient to confirm "impairment or disturbance of the mind".

Nature of decision

Assessors should record the key decisions facing clients/patients

Test

1. **Understanding the information**

    The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process

2. **Retaining the information**

    Information only needs to be held in the mind of the person long enough to make the decision.

3. **Use or weigh the information**

    Some people can understand the information, but an impairment stops them from using it. Whereas others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could foresee the consequences of making, or failing to make, that decision.

4. **Communicate the decision**

    Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc).

Protocol for Assessing Capacity

1. Read Information sheet once to participant

2. Read the following part of the Information sheet: "We would like to find out about your health and some of the health problems you may have. MHC have a file about you. This file has things like what tablets you take and what health problems you have in it.

Ask the participant: "**Why do I want to collect data from your file?**"

Score 1 if the person gives an answer similar to "To find out about my health" or "To see if I'm sick".
Score 0 if the answer is irrelevant or too vague (eg "See me").

3. Read the following part of the Information sheet: "We would like your permission to use some data from your file, to see what health problems you have and to see if they are similar to what other people have".

Ask the participant: "**What do I want to find out?**".
Score 1 for correct answer (e.g. "to see what health problems people have…compare me to others")
Score 0 for incorrect answer or an answer that is too vague.

4. Read the following part of the Information sheet: "We will put the information on to a computer with a password, but we won't use your name, age or address"

Ask the participant "**Are you happy for me to come to collect this information?**"

Answers Yes or No.

Ask the participant: "**Are you happy for me to share the information to help other people with a learning disability?**

Answers Yes or No.

For consent to be given the participant needs to answer Yes to both questions.

5. Read the following part of the Information sheet: "If you say yes, but then you change your mind that's OK. It's OK to say no if you want to. You can say no now, or if you change your mind later. You can tell us, or a member of staff at any time"

Ask the participant: "**What will you do if you change your mind?**".
Score 1 for any answer similar to "Tell you No".
Score 0 if answer is irrelevant or too vague.

Overall Scoring

If the participant scores 0 to any of the questions under items 2,3 or 5, then the participant is assessed as not having the capacity to consent in this specific context. The assessment should be repeated at another time if possible. If the outcome is the same the researchers should follow the alternative route of seeking consent through the legal representatives and the "Best Interests Meeting".

If the participant scores 1 in every question under items 2,3,4 and 6 and answers "Yes" to both questions under item 4, then the participant is assessed as having the capacity to consent and s/he is indicating their wish to participate. If the participant scores 1 in every question under items 2,3 and 6 but answers "No" in either question 4, the participant is assessed as having the capacity to consent and is indicating his refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11(1)*, 77-83.

Appendix O
Health Census: Consent Form- Participants with Intellectual Disabilities

CONSENT

1. I have been given information about the study

    YES   NO

2. I have been able to ask questions if I wanted

    YES   NO

3. I know that I can say no at any time

    YES   NO

4. I am happy for my information to be used

    YES   NO

Written Consent

Signed……………………………………………………………

Date…………………………………………………………

Witnessed by………………………………………………..
Name…………………………………………………...
Position…………………………………………………
Date & Time……………………………………………

Researcher…………………………………………………
Name…………………………………………………
Date & Time…………………………………………

Cydsyniad

1. Rwyf wedi derbyn gwybodaeth am yr ymchwil

   YDW   NAC YDW

2. Rwyf wedi cael y cyfle i ofyn cwestiynau

   YDW   NAC YDW

3. Rwyf yn gwybod gallaf ddweud na ar unrhyw adeg

   YDW   NAC YDW

4. Rwyf yn hapus i fy ngwybodaeth cael ei defnyddio

   YDW   NAC YDW

Cydsyniad Ysgrifenedig

Llofnod…………………………………………………………

Dyddiad…………………………………………………………..

Cydsyniad ar lafar

       IE   **NA**   **N/A**

Tystiwyd gan……………………………………………………......

Enw………………………………………………………………

Swydd……………………………………………………………

Dyddiad & Amser…………………………………………………

Ymchwilydd………………………………………..……………

Enw……………………………………………………………….

Dyddiad & Amser…………………………………..……………

Appendix P
Health Census: Best Interests Checklist

Mental Capacity Act 2005
Best Interests Checklist
CONFIDENTIAL

Name…………………………………………………………………………..

DoB………………...

Preferred Language……………………………………………………………

Name of
Unit………………………………………………………………………………

Decision/Intervention proposed

Checklist

1. Have you considered, so as far as is practicable, that the person may regain capacity at some time in the future and whether a delay in decision-making is possible which will allow the person to make that decision themselves at a later date?

                                  YES   **NO**

    Please give details below

2. Have you considered as far as is practicable that person's involvement in actions proposed on their behalf or in any decisions affecting them?

                                  YES   **NO**

    Please give details below

3. Have you considered the beliefs and values that the person's past and present wishes and preferences about the matter in question?

                                  YES   **NO**

    Please give details below

4. Have you taken into account other factors that the person had when capable, that would likely influence the person's attitude to the decision in question (religion, culture, lifestyle etc.)?

                                                              YES   **NO**

    Please give details below

5. Have you taken into account other factors that the person would be likely, if they were capable, to consider in relation to the matter (emotional bonds, family obligations, deciding how to spend money etc.)?

                                                              YES   **NO**

    Please give details below

6. Have you consulted and taken into account the views of other key persons as to what would be in the person's best interests and taken into considerations their wishes, feelings, beliefs, values etc.?

                                                              YES   **NO**

    Please give details below

7. Any disagreements, conflicts, doubts expressed by any parties during this assessment & methods used to resolve these?
    Give details

8. **Has a referral been made to the Best Interests Meeting?**

                                                                    YES   **NO**

   Give details (including date)

9. **Has a referral been made to an IMCA?**

                                                                    YES   **NO**

   Give details (including date)

Details of Assessor

Name…………………………………………………………………………

Nature of professional relationship………………………………………………..

Nature of interest (financial or other) in matter for which assessment was carried out

…………………………………………………………………………………

…………………………………………………………………………………

Signed…………………………………………………………………………

Date & Time…………………………………………………………………

Details of Witness

Name…………………………………………………………………………

Nature of professional relationship…………………………………………………

Signed…………………………………………………………………………

Date & Time…………………………………………………………………

Appendix Q
Health Census: Proxy Consent Form

Proxy Consent Form

The Physical Health of Adults with Intellectual Disabilities Living in Residential

& Community Services

Please tick

☐   I confirm that I have read and understand the information sheet for the above

study and have had the opportunity to ask questions.

☐   I understand that participation is voluntary and that I am free to withdraw my

relative/client at any time without giving any reason. This will not affect the

care or legal rights of my relative/client.

☐   I therefore agree on behalf of ………………………………………….

that researchers can collect data & anonymous data may be summarised,

potentially for publication

_____   _____   _____

Name of person giving consent   Date   Signature

_____   _____

Relationship to participant   Contact details

_____   _____   _____

Researcher   Date   Signature

Appendix R
Health Census: Best Interests Letter

School of Psychology,

Bangor University,

Bangor,

Gwynedd,

LL57 2AS

01248 388656

19/07/2010

Dear _____

     We are currently conducting research, in Mental Health Care UK (MHC), looking into the physical and mental health needs of adults with learning disabilities. This research is being conducted using information from clients' case notes, which is routinely collected as part of the review of every client. As part of this research we need to obtain informed consent from clients to allow us to access and use information in their file.

     We would therefore like to ask you to consider if taking part in this study would be in _____best interests. If you think that taking part in this research is in their best interests, could you please complete the attached "Proxy Consent form" and return it to us in the envelope provided, or alternatively contact us to arrange a meeting.

     Please find enclosed copies staff and participant information sheets.

If you have any questions please don't hesitate to contact us,

Yours sincerely,

Ceri Jones

Supervised by:

Professor Richard Hastings   Deborah Roberts

                                    Clinical Lead MHC

Appendix S
Systematic Review & Meta Analysis Checklist

		YES	NO
First Author:			
3 first words in title of paper:			
Year Published:			
General		**YES**	**NO**
1	Full paper available		
2	English language		
3	Results not published in another paper		
4	Peer reviewed article (not a dissertation, book chapter, conference presentation)		
Methodology: Participants			
5	Adults only (NOT a mixed group of adults and adolescents. Aged 18+)		
6	People with an Intellectual Disability. Must include at least a separate group of people with an intellectual disability only. ID defined as IQ data, may be administratively defined (e.g. clearly in receipt of ID services) or clearly referred to as a sample of people with ID ND there are NO contradicting data (e.g. mean IQ over 70 and range into 80s)		
Methodology: Intervention			
7	Multi-component intervention to reduce weight/ BMI to include at least 2 of the following:		
a	Diet: Calorie restriction, increase fruit and veg. consumption, promote healthy choices		
b	Physical Activity: moderate intensity PA – aim for 30 minutes, 5 days a week		
c	Behaviour Modification Techniques: self-monitoring, stimulus control, goal setting, slowing rate of eating, social support, problem solving, assertiveness, cognitive restructuring, reinforcement of change, relapse prevention strategies for dealing with weight gain		
d	Health Education/ Promotion any intervention which teaches the benefits of a healthy lifestyle		
8	Intervention is fully described clear detail on the components of the intervention		
9	Intervention is surgical or pharmacological exclude if surgery or pharmacological treatment is combined with 7a-d due to potential bias		
Methodology: Measures/ Results			
10	Must include BMI or weight data		
Methodology: Design			
11	Minimum of pre- and post-intervention data if follow-up data must include post-intervention data too		
12	Not a single-case study or a descriptive study		
*	**INCLUDE in analysis:** Inclusion criteria YES to 1,2,3,4,5,6,7,8,10,11,12 **Exclude from analysis:** Exclude if YES to: 9		
Comments/ Questions:			
Scorer's initials & date			
Copy of paper available (Yes/ No & Location)			

Appendix T
Intellectual Disability Service Report and Raw Data

NOTE:
THIS IS A VERSION OF THE FULL REPORT THAT THE SERVICE RECEIVED.
DUE TO CONFIDENTIALITY, THE FULL REPORT WAS NOT SUITABLE FOR INCLUSION IN THIS THESIS.

Intellectual Disability Service Report and Raw Data
CONTENT

1. **Summary**

2. **Measures**

3. **Results**

4. **Conclusions & Implications**

5. **References**

6. **Appendix - Data**

   Background Information

   > 1. Age
   >
   > 2. Gender

   Information from the OK Health Check

   > 3. – 23.

   Information from the Health of the Nation Outcome Scales-Learning Disability (HoNOS-LD).

   Information from the Reiss Screen

   Information from the Glasgow Depression Scale (GDS)

   Information from the Behaviour Problem Inventory (BPI)

   Information from the Proxy Respondent International Physical Activity Questionnaire (IPAQ-pr)

1. Summary

This report presents the findings of the "Health Census" conducted between May and November 2010. The report focuses on the physical and mental health of people with ID currently residing within the service, as well as health-related lifestyle risks. The benefits of this research are that the findings are from a large proportion of adults with ID from within one service.

This summary presents the report's key findings:

- 6.6% of participants were underweight, 21.7% were overweight, 30.3% were obese and 11.3% were morbidly obese.
- Poly-pharmacy is common, with 60.4% of participants taking 6 or more different medications on a daily basis.
- 63.3% of participants experience frequent, occasional or periodical pain.
- 5.7% of participants have hypotension and 19.8% have hypertension.
- 8.8% of participants have oedema, 11.3% have trouble breathing and/or asthma and 8.5% have a chronic or congenital circulatory or pulmonary disorder.
- 34.9% of participants are incontinent and this pattern of incontinence has recently changed for 5.7%.
- 38.7% of participants have epilepsy and 78% of these take anti-convulsant medication.
- 27.4% of participants have regular constipation and/or loose motions and 11% experience regular discomfort, which originates from the digestive system.
- 6.6% of participants had moles or other skin marks, which weren't present at the last examination, 28.3% suffered from rashes, irritation or frequent itching.
- 17% of participants are permanently physically handicapped and 25.5% have impaired gross motor activity.
- 15.1% of participants have obvious problems with the shape of their feet, 7.5% have chronic foot problems and 30.2% have circulation problems in relation to their feet.
- 10.4% of participants have painful or sensitive teeth and 8.5% use dentures.
- 34% of participants have obvious defects with their eyes and/or vision.
- 11.3% of participants have obvious problems with their ears and hearing.
- 100% of the women who regularly menstruate experience physiological and psychological problems in relation to their menstruation.
- 22.7% of participants experience problems with their sleep and 6.6% receive night sedation to assist their sleep.

- Mental health problems include emotional distress (30.2%), irrational mood swings (57.6%), altered perceptions (35.8%), irrational fears and anxieties (30.2%), obsessional behaviours (55.7%), psychosomatic disorders (6.6%) and frequent headaches (11.3%).

- 27.4% of participants (according to the "OK Health Check") take sufficient exercise, 20.8% smoke, 0.9% use cannabis.

- 20.8% of participants experience frequent stressors, such as not having access to money, new people, places or environments and change to routine.

- Over a third of participants have mild, moderate or significant problems according to the HoNOS-LD.

- Less than 10% of participants met the cut-off on the total scores for maladaptive behaviours as recorded on the Reiss Screen.

- 10.4% of participants, according to the Glasgow Depression Scale, have symptoms suggestive of the need for further screening for depression.

- Under half of participants had significant problem behaviours in the three domains of the BPI.

- Data from the proxy-IPAQ revealed that 50.9% of participants engage in low levels of physical activity (less than 5 days a week walking or doing moderate intensity physical activity for 30 minutes a day).

The implications of these findings are:

- BMI data shows that 67% of clients are overweight, obese or morbidly obese. Previous research has shown the effectiveness of dietary management, healthy eating and physical activity in reducing BMI in adults with ID. We recommend that the service promotes a healthy lifestyle for all service users. The service should support people who are overweight or obese to lose weight.

- 72.6% of participants do not take sufficient exercise. The service should support all clients to be more physically active.

- 20.8% of participants smoke. We recommend that the service consider ways to support clients to stop smoking or to reduce the amount that clients smoke.

2. Measures

The Ok Health Check

Specifically developed for adults with ID, the "OK Health Check" (Matthews, 1997) is a checklist to identify and assess physical health needs. The "OK Health Check" identifies symptoms relating to all of the bodily systems, such as the gastrointestinal, respiratory, cardiovascular and neurological systems, as well as assessing dental disease, epilepsy, mental health problems and problems with hearing and vision. Inter-rater reliability and construct validity are reported as good (Matthews, 1997). The OK Health Check is widely used within the community (Gates, 2006). The "OK Health Check" is completed on each client on admission to the service and is updated every 6 months as part of each client's progress review. The "OK Health Checks" were completed by clinical nurses and senior support staff at the service.

The "OK Health Check" is a very useful record of physical and mental health needs, as it assesses signs and symptoms relating to all of the bodily systems. It also signifies when reviews (e.g. medication) and screening (e.g. breast, cervical) are required. Through the use of the "Don't know" boxes, staff should be able to ask for expert opinion should it be necessary (e.g. GP, physiotherapist, SALT).

Adaptive Behaviour Assessment System (2nd Edition; ABAS-II)

The ABAS-II (Harrison & Oakland, 2003) is a comprehensive norm-referenced measure that assesses the adaptive skills of individuals from birth to 89 years. The ABAS-II measures individuals' daily living and adaptive skills, including conceptual reasoning, social interactions and practical functioning. Internal consistency, test-retest reliability, inter-rater reliability and content validity are all reported as good (Harrison & Oakland, 2003). The ABAS-II is completed on each client on admission to the service and is updated every 6 months as part of each client's progress review. Clinical nurse specialists or clinical psychologists completed all of ABAS-II assessments.

The ABAS-II is a very useful measure, which correlates with IQ (Wechsler Adult Intelligence Scale; Harrison & Oakland, 2003) and gives an accurate picture of

an individual's level of functioning in different areas. By repeated use, the ABAS-II should provide an indication of change in an individual's level of functioning, through gains, as a result of skill acquisition, or loss, suggesting that further screening (e.g. for dementia) is required (Rust & Wallace, 2004).

The Health of the Nation Outcome Scales – Learning Disabilities (HoNOS-LD)

HoNOS-LD (Roy, Matthews, Clifford, Fowler & Martin, 2002) was adapted for use with adults, aged 18-65, with an ID and provides a method of measuring change in behaviours, functioning and mental health problems. As the HoNOS-LD is designed to be used twice, it can measure change following treatment, or decline, in people with ID who have additional mental health needs. Inter-rater reliability and content validity are reported as good (Roy *et al.*, 2002). The HoNOS-LD is completed on each client on admission to the service and is updated every 3 months. All HoNOS-LD assessments at the service were completed by clinical nurse specialists or clinical psychologists.

The HoNOS-LD's main advantage is that it is commonly used to measure change over a period of time in individuals' functioning, behaviours and mental health.

Reiss Screen for Maladaptive Behaviour (RSMB)

The RSMB (Reiss, 1988) is a standardised screening instrument for mental health disorders in adults with ID. The RSMB has been shown to have good internal, inter-rater and test-retest reliability (Reiss, 1988; Rojahn, Warren & Ohringer, 1994) and good criterion and concurrent validity (Reiss, 1988). The RSMB is completed on each client on admission to the service and is updated annually as part of each client's progress review. All Reiss Screen assessments were completed by clinical nurse specialists or by the clinical psychologists at the service.

The RSMB, although useful as a screening tool for problematic behaviours does not allow the frequency or severity of these behaviours to be recorded individually.

Glasgow Depression Scale (Learning Disabilities; GDS-LD)

The GDS-LD (Cuthill, Espie & Cooper, 2003) is used to identify and monitor depression in adults with ID. Internal consistency, test-retest reliability and criterion validity are all high for the GDS-LD, and specificity and sensitivity are reported as 90% and 96% respectively (Cuthill *et al.*, 2003). The GDS-LD is currently completed on all clients in the service and is updated every annually as part of each client's progress review. All GDS-LD assessments were completed by the clinical nurse specialists and clinical psychologists at the service.

The GDS can be used to measure change in symptoms, both as a result of interventions or as a result of deterioration of condition, as well as being used as a screening tool for depression in adults with ID. Cuthill and colleagues (2003) identified a clinical cut off point, which if reached, suggests that individuals should be referred for more specialised screening.

Behaviour Problem Inventory (BPI)

The BPI (Rojahn, Matson, Lott, Esbenser & Smalls, 2001) assesses the frequency and severity of self-injurious, stereotypic, aggressive and destructive behaviours in adults with ID. The BPI has good internal consistency, test-retest reliability and inter-rater reliability, while factor validity is reported as good for all 52 items (Rojahn et al., 2001). The BPI is completed on all clients within ID services and is updated annually as part of the review process. All BPI assessments were completed by the clinical nurse specialists and clinical psychologists at the service.

The main advantages of the BPI, unlike the RSMB, are that it assesses the severity and the frequency of problematic behaviours. This information provides a more accurate description of the behaviours displayed by clients.

International Physical Activity Questionnaire (IPAQ) – Proxy Respondent Version

The IPAQ (Craig, Marshall, Sjostrom, Bauman, Booth, Ainsworth, Pratt, Ekelund, Yngve, & Sallis, 2003) comprises of four questionnaires, with long and short versions for use by either telephone or self-administration. The questionnaires can be used to obtain internationally comparable data on health-related physical activity. Extensive reliability and validity testing was conducted across 12 countries.

The results showed that the IPAQ had acceptable psychometric properties to be used for 18-65 year old adults in diverse settings. The IPAQ is also suitable for national population-based prevalence studies of participation in physical activity. In this study, a proxy respondent version, that we developed, based on the IPAQ was used to assess how many minutes a client spends participating in physical activity, of different intensities, during a week.

The advantages of the proxy-IPAQ were that it relies on support staff to complete it on a daily basis, rather than depending on their own (and the participants') memory to recall physical activity data a week later. Providing that they are filled in accurately, the IPAQ should provide a good estimate of the physical activity of different intensities done during a week. Although pedometers and accelerometers would provide this information, perhaps in more detail and with more accuracy, the IPAQ provides a much cheaper alternative.

Methodology

This project was subject to full ethics and governance review by the School of Psychology, Bangor University. All clients with an ID at the service were seen. Staff and clients were given study information sheets and the researchers talked through the information sheets with clients and staff. Ample opportunity was given for clients and staff to ask questions. A functional assessment of capacity was completed on each client, to see if they understood the research process. If the client had capacity then the researchers asked for informed consent. If the client did not have capacity then the researchers completed a best interests checklist. A proxy consent form was sent to relatives or purchasers and if no response was received a best interests meeting was arranged, inviting family members, purchasers and IMCAs where necessary. If consent was obtained, from the client, from proxy consent, or as a result of the best interests meeting, data from a client's file were collected, anonymised and summarised for research purposes.

3. Results

<u>See Appendix for all the summarized Raw Data</u>

Information from the "OK Health Check"

<u>Body Mass Index (BMI)</u>

BMI is a fairly reliable indicator of body fatness and is commonly used as an alternative method for measuring body fat, especially for population-based studies of obesity. BMI is calculated by dividing a person's weight, measured in kilograms, by their height, measured in meters, which is squared, using the equation:

$$BMI = \frac{Weight\ (kg)}{Height^2\ (m)}$$

28 (26.32%) participants were classed as being of normal weight (BMI 19-24.5), 6 (6.32%) were classed as being underweight (BMI <18.5). The remainder were classed as overweight (BMI 25-30; 21 (22.11%) participants), obese (BMI 30-40; 30 (31.58%) participants) and morbidly obese (BMI >40; 13 (13.68%) participants).

<u>Medication</u>

Polypharmacy (using 6 or more different types of medication; Fulton and Allen, 2005) was common with 47 (49.47%) participants taking 6 or more different types of medication on a daily basis. On average, participants were taking 6.41 different medications on a daily basis (range 0-18, SD=3.64, SE=0.35). The frequency of medication use, and the types of medication used, is shown in the appendix. Polypharmacy is a risk factor for adverse drug reactions (ADR; Fulton & Allen, 2005). The OK Health Check data of only 16 (15.1%) participants reported that staff were fully aware of the potential side effects of the medication that these participants received.

<u>Pain</u>

98 (96.08%) participants had the ability to express when they were in pain. 67 (65.7%) participants were reported to experience frequent, occasional or periodical pain.

<u>Circulation & Breathing</u>

Data on pulse and respiratory rate were only reported for 42 (41.2%) and 32

(31.3%) participants respectively. Data on blood pressure (BP) was provided for 41 (40.2%) participants and revealed that 14 (13.7%) participants had normal blood pressure, 6 (5.8%) had hypotension (low BP) and 21 (20.6%) had hypertension (high BP).

Signs of cardiovascular and respiratory problems were reported as 9 (8.8%) having oedema, 0 (0%) having cyanosis, 1 (0.9%) having signs of cardio-pulmonary disorder, 12 (11.76%) having trouble breathing, asthma or a troublesome cough, 9 (8.8%) having chronic or congenital circulatory or pulmonary disorder and 2 (1.8%) having varicose veins.

Genito-Urinary System

37 (36.3%) participants were reported as being incontinent during the day or the night and the pattern of incontinence had changed recently for 6 (5.9%) participants. 2 (1.8%) participants were reported as having trouble passing urine and 2 (1.8%) were reported as having abnormally coloured or smelling urine.

Epilepsy

41 (40.2%) participants were reported as having epilepsy. Of these, all (100%) had accurate records of their seizures maintained, only 1 (2.4%) participant had a recent change in the frequency or pattern of seizures. 32 (78%) of the participants with epilepsy received anti-convulsant medication, with 26 (63.5%) of these taking anti-convulsants which require routine blood testing to ensure that the anti-convulants are not effecting other bodily systems, most notably the liver (Rang, Dale, Ritter & Flower, 2007).

Digestion & Elimination

15 (14.7%) participants were noted as having a diet that was deficient, while 26 (24.5%) participants received a "special diet". 92 (90.2%) of participants were reported as drinking adequate fluids on a daily basis. 29 (28.4%) participants have regular constipation and/or loose motions, while 8 (7.8%) have abnormally coloured motions. 11 (10.8%) participants experience frequent discomfort that originates from the digestive system or bowel, while 16 (15.7%) participants are reported as having a chronic digestive condition. 22 (21.6%) participants have a difficulty or reluctance to

eat, or are reported as having "peculiar" eating habits.

Skin

The "OK Health Check" revealed that 30 (29.4%) participants had a rash, irritation or itching, 7 (6.6%) participants had moles or other skin marks which weren't present at the last examination, or that had changed recently, 4 (3.9%) had pressures areas which become inflamed on a regular basis, 22 (21.6%) had damaged or broken skin, 23 (22.5%) had a chronic or long standing skin condition, while 12 (11.7%) suffered from offensive body odour or another personal hygiene problem.

Physique & Mobility

18 participants (17.6%) were reported as being permanently physically handicapped, 27 (256.5%) had impaired gross motor activity and dexterity, 26 (25.5%) had difficulty coordinating movement and/or hand-eye coordination, 27 (26.5%) had persistently poor posture, stooping or spinal curvatures, 4 (3.9%) had contractures, 31 (30.4%) had evidence or tremors, twitches or other uncontrolled movements, 9 (8.8%) were reported as having myoclonic spasms, 4 (3.9%) had loss of movement or pain on movement, 9 (8.8%) had muscle wasting. 18 (17.6%) of participants were reported as using mobility or positional aids.

Feet

16 (15.7%) participants were reported as having an obvious problem in relation to the shape of their feet, 15 (14.7%) had skin problems on the feet and/or between the toes, which included itching and discomfort, 11 (10.8%) had toe nails which were thick, misshapen or abnormal, 7 (6.8%) were reported as having pain in the feet, 8 (7.8%) had a chronic foot problem and 32 (31.4%) had evidence of circulatory problems in relation to the feet.

Oral Hygiene

86 (84.3%) participants were reported as having regular dental checks, while 95 (93.1%) of participants were reported as having any teeth. 24 (23.5%) participants were reported as having obvious problems with their teeth and/or gums, while 16 (15.7%) have difficulties chewing, 19 (18.6%) have persistently offensive breath, 8 (7.8%) dribble excessively, 3 (2.9%) have a chronic mouth condition, 2 (1.9%) have

frequent mouth sores and/or ulcers, 11 (10.8%) are reported as having painful or sensitive teeth, 9 (8.8%) have dentures and all (100%) wear them on a regular basis.

Eyes and Vision

36 (35.3%) of participants were reported a shaving an obvious defect with their eyes and/or vision, 8 (7.8%) have an obvious opacity of their eyes (cataracts), 10 (9.8%) display behaviours which may suggest discomfort or other problems of they eyes, while 10 (9.8%) display behaviours which suggest problems of vision, 3 (2.9%) suffer from frequent discomfort of the eyelids and 39 (38.2%) wear spectacles.

Ears and Hearing

12 (11.8%) of the participants were reported as having an obvious ear problem, 10 (9.8%) display behaviours which would suggest a hearing problem, 17 (16.7%) have a history of ear problems, 20 (19.6%) have frequent impacted or excessive ear wax and 3 (2.9%) use a hearing aid.

Female Sexual Health

9 (26.5%) of the 34 women have had a breast examination, while 12 (35.3%) have had a cervical smear, 19 (55.9%) of the women menstruate regularly and all (100%) have physical or psychological problems associated with their menstrual cycle. 6 (17.6%) of the women experience frequent discomfort or itching of the anus, perineum or genitals.

Male Sexual Health

13 (21.3%) of the 61 men had had a testicular /genital examination, 3 (4.9%) of the men dribble after passing urine and 1 (1.6%) of the men experienced frequent discomfort or itching of the anus, perineum or genitals.

Sleep

24 (23.5%) participants experience a disturbed pattern of sleep, 13 (12.7%) participants are reported as staying awake for much of the night, while 23 (22.5%) participants sleep for much of the day. 7 (6.8%) participants use night sedation to assist their sleep.

Mental Health

32 (31.4%) of participants experience frequent emotional distress, 44 (43.1%) experience irrational mood swings, 38 (37.3%) experience altered perceptions, 32 (31.4%) display irrational fears and/or anxieties, 59 (57.8%) display obsessional behaviours, 7 (6.9%) display psychosomatic disorders, 12 (11.8%) have frequent or periodic headaches.

Lifestyle Risks

29 (28.4%) participants are reported as taking sufficient regular exercise. 22 (21.6%) participants are reported as smokers, with participants smoking on average 26.36 cigarettes a day (range 10-60, SD=13.62, SE=2.90). 8 (7.8%) participants are reported to drink alcohol occasionally. 1 (0.9%) participant uses illicit drugs (cannabis) on a regular basis. 70 (68.6%) participants do not display self-injurious behaviour (S.I.B). Of the remainder, the most common forms of SIB are hitting their face, biting, hitting their bodies, scratching their bodies and faces (see appendix for all the SIB data including frequencies).

Stressors

No stressors were noted for 84 (82.5%) participants. The most common stressors were not having access to money, new places/people/environments, change to routine and other services users (see appendix for all the stressors data including frequencies).

Other Health Information

The table in the appendix shows the frequency of physical and mental health conditions. The table shows that epilepsy is the most common physical condition that affects participants, followed by hypertension (high blood pressure), hypersensitivity (e.g. having an allergy) and gastro-oesophageal reflux disease (GORD aka GERD) and hyperlipidaemia (high cholesterol). Participants on average had 4.54 physical and mental health conditions (range 0-11, SD=2.59, SE=0.26).

Information from the Health of the Nation Outcome Scales – Learning Disability (HoNOS-LD)

The data in the appendix shows the individual responses for the HoNOS-LD.

Although the HoNOS-LD does not have a clinical cut-off point for individual sub-scales, the items are classed as significant if they are reported as mild, moderate or severe. Data shows that 41 (40.2%) participants have mild, moderate or severe behaviour problems that are directed at others, 26 (25.4%) participants have mild, moderate or severe behaviour problems that are directed at themselves, 49 (48.0%) participants have mild, moderate or severe mental and other behaviour problems, 49 (48.0%) participants have mild, moderate or severe problems with attention and concentration, 39 (38.2%) participants have mild, moderate or severe problems with memory and orientation, 30 (29.4%) participants have mild, moderate or severe problems with communication (understanding), 34 (33.3%) participants have mild, moderate or severe problems with communication (expression), 20 (19.6%) participants have mild, moderate or severe hallucinations and delusions, 30 (29.4%) participants have mild, moderate or severe mood changes, 23 (22.5%) participants have mild, moderate or severe problems sleeping, 14 (13.7%) participants have mild, moderate or severe problems associated with eating and/or drinking, 20 (19.6%) participants have mild, moderate or severe physical problems, 16 (15.7%) participants have mild, moderate or severe seizures, 33 (32.4%) participants have mild, moderate or severe problems with activities of daily living (ADL; Home), 50 (49.0%) participants have mild, moderate or severe with ADL (other), 29 (28.4%) participants have mild, moderate or severe problems in relation to their self-care, 27 (26.5%) participants have mild, moderate or severe problems with relationships and 47 (46.1%) participants have mild, moderate or severe have problems with occupation and/or activities.

Information from the Reiss Screen

Raw data for all of the individual items of the Reiss screen is shown in the appendix. The Reiss screen uses a cut-off score of 9, for each of the sub-scales, to signify a clinically significant level of mental health problems. 11 (10.8%) participants had clinically significant aggression, 2 (1.9%) participants had clinically significant autism, 4 (3.9%) participants had clinically significant psychosis, 6 (5.9%) participants had clinically significant paranoia, 6 (5.9%) participants had clinically significant depression (B; Behavioural scale), 5 (4.9%) participants had clinically significant depression (P; Physical scale), 5 (4.9%) participants had clinically significant avoidant behaviour and 2 (1.9%) participants had clinically significant

other maladaptive behaviour, which included drug and alcohol problems, over-activity, SIB, sexual problems, stealing and suicidal behaviours. In total 14 (13.7%) of participants met the cut-off scores for at least one sub-scale on the Reiss Screen.

Information from the Glasgow Depression Scale (GDS)

11 (10.8%) participants scored above 13, which is the clinical cut-off point for the GDS. A score above 13 suggests that a participant may have depression therefore referral for a more thorough assessment is recommended.

Information from the Behaviour Problem Inventory (BPI)

The BPI does not have cut-off scores to suggest clinically significant problem behaviours. However, for the purposes of this study a cut-off score of 7 was chosen for each individual item of the sub-scales. This number was chosen as it takes into account mild problems, which occur frequently, and severe problems that do not occur that often. The results for each problem behaviour are shown in the appendix.

For the sub-scales scores, participants were classed as having a clinically significant behaviour problem if they scored more than 7 for any of the individual items in that scale. 34 (33.3%) participants had clinically significant self-injurious behavior, 51 (50.0%) participants had clinically significant stereotyped behaviour and 44 (43.1%) participants had clinically significant aggressive or destructive behaviour.

Information from the International Physical Activity Questionnaire (proxy IPAQ)

The results show that participants engage in low levels of physical activity. During a period of 1 week, 1 participant (0.9%) did not do any physical activity, 54 (52.9%) participants did low levels of physical activity, 42 (41.2%) participants did moderate levels of physical activity and 5 (4.9%) participants did high levels of physical activity.

Information from Comparative Data

Comparative data from the Welsh Health Survey 2009 (Welsh Assembly Government, 2010) and the Adults with learning difficulties in England 2003/4 (Emerson, Malam, Davies & Spencer, 2005) were used. These comparisons are a rough guideline only of areas where the sample of THE SERVICE clients were

reported as having increased or decreased problems compared to other studies of adults, with and without ID, in the UK.

Frequency of Physical and Mental Health Conditions

Data showed that epilepsy was more common in the service sample than in the English ID sample (40.0 vs. 16% respectively); hypertension was more common in the service sample than the Welsh normative sample (20.6% vs. 20% respectively); asthma was higher in the service compared to the English ID sample (11.7% vs. 2% respectively) and was slightly higher than the Welsh normative sample (11.7 vs. 10% respectively); Type 2 diabetes was higher in the service sample compared to the English ID and Welsh normative sample (7.5 vs. 2% vs. 6% respectively); heart disease was higher in the the sample compared to the English ID and the Welsh normative sample (6.6% vs. 2% vs. 4% respectively); dementia was higher in the service compared to the normative Welsh sample (3.8% vs. 1%). The prevalence of lung disease was similar for the service and the Welsh normative sample (2.8% vs. 3% respectively) and cerebral palsy was as prevalent in the service as in the English ID data (1.9% vs. 2% respectively). The prevalence of rheumatoid arthritis was lower in the service compared to the Welsh normative sample (2% vs. 13%); the prevalence of type 1 diabetes was also lower in this sample compared to the English ID sample and the Welsh normative sample (0.9% vs. 2% vs. 6% respectively).

Comparative data were also available for mental health problems, but only from the Welsh normative sample. Data showed that psychosis was more common in this sample (37.3% vs. 1%), as was depression (31.1% vs. 8%), anxiety (25.5% vs. 6%) and schizotypal disorders (9.4% vs. 1%).

Frequency of Smoking

The prevalence of smoking in the service sample was slightly higher than the English ID sample but lower than the normative Welsh sample (21.05% vs. 19% vs. 24% respectively).

Frequency of Alcohol use

The prevalence of alcohol use in the sample was lower than the normative Welsh sample (8% vs. 88% respectively).

Information from the proxy IPAQ

46.32% of participants in the service currently meet the WHO (2005) guidelines for 30 minutes of physical activity on 5 or more days a week. This is a higher percentage compared to the English ID sample (24.20%) and the Welsh normative sample (29%).

Current BMI

Comparative data was available from the Welsh normative sample and showed that the sample had a higher frequency of people being underweight (6.32% vs. 2% respectively), a lower frequency of people being the desired weight (26.32% vs. 41% respectively); a lower frequency of people being overweight (22.11% vs. 36%) and a higher level of people being obese (obese and morbidly obese; 45.26% vs. 21%).

4. Conclusions & Implications

Implications from the results of the "OK Health Check"

The BMI data shows that 67% of clients were above the desired weight for their height, being classed as overweight, obese or morbidly obese. Being overweight is associated with cardiovascular disease, hypertension, type II diabetes, breast, prostate and colon cancers, osteoarthritis, and is known to be a cause of reduced life expectancy in adults with ID (Hamilton, Hankey, Miller, Boyle & Melville, 2007). Dietary management, healthy eating and physical activity interventions have all been shown to be successful in reducing BMI in adults with ID (Prasher & Janicki, 2002). We recommend that the service designs ways to support clients to improve their BMI.

72.6% of participants, according to the "OK Health Check" do not take sufficient exercise. It is recommended that everyone does 30 minutes of moderate intensity exercise on at least 5 days of the week (World Health Organisation; WHO, 2005). Low levels of physical activity were also reported by the proxy-IPAQ. The service needs to support clients to increase their physical activity levels.

20.8% of participants smoke. Smoking is associated with vascular and respiratory diseases as well as cancers of the respiratory system and the mouth (Doll, Peto, Boreham & Sutherland, 2004). We recommend that the service consider ways to support clients to stop smoking or reduce the amount that clients smoke.

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Appendix - Data

1. Age

Age	Total
16-24	7
25-34	17
35-44	38
45-54	22
55-64	10
65+	8
TOTAL	102

2. Gender

Gender	Total
Male	61
Female	34
TOTAL	102

Information from the OK Health Check

3. Particular clinical syndrome or congenital condition

Cause of Intellectual Disability	Total
Not Known	73
Autistic Spectrum Disorder	14
Down Syndrome	5
Rett Syndrome	1
Prader-Willi Syndrome	1
Childhood Illness (Meningitis)	1
Turner Syndrome	1
Fragile X	1
Oral-Facial-Digital Syndrome	1
Ring 13 Syndrome	1
Moebius Syndrome	1
Phenylketonuria	1
Cyanosis at birth	1
TOTAL	102

4. Body Mass Index

a. Current Body Mass Index

BMI	Total
Underweight (<18.5)	6
Normal (19-24.5)	25
Overweight (25-30)	21
Obese (30-40)	30
Morbidly Obese (40+)	13
TOTAL	102

b. Changes in Body Mass Index

	Total
Increase	31
Decrease	42
Remained the same	1
No previous data	28
TOTAL	102

5. Current Medication

a. Classification of Medication Used

Medication	Frequency
Anti epileptics	90
Antipsychotics	80
Analgesics – non-opioid	59
Hypnotics & anxiolytics	37
Laxatives	29
Ulcer-healing	26
Antidepressants – SSRI	26
Sedatives	24
Antihistamines	20
Motility stimulants	20
Antimuscarinic (movement disorders)	20
Lipid-regulating	17
Topical – emollients & barriers	17
Bronchodilators	16
Thyroid hormones	16
Oral antidiabetics	13
Supplements – minerals	11
Diuretics	11
Analgesics – opioid	11
Antidepressants – tricyclic	7
Contraceptives – progesterone only	6
Beta-Blockers	6
Supplements – vitamins	6
Antimanic	6
Antiplatelets	5
Drugs acting on nose	5
Topical – corticosteroids	5
Antacids	5
Supplements – oral nutrition	5

Anti-hypertensives (NOS)	5
Drugs acting on eyes	5
Calcium Channel Blockers	5
Vasodilators	5
Anti-emetics	4
Antidepressants – MO inhibitors	4
Anti-Obesity	3
Anticoagulants	3
Topical- Anti-infective	3
Antibacterials	3
Drugs for anaemias	3
CNS stimulants	2
Migraines & cluster headaches	2
Dementia	2
Non-steroidal anti-inflammatory	2
Anti motility	2
Antiviral	2
Male sex hormone antagonists	2
Bone metabolism –aides	2
Chronic Bowel Disorders	2
Sex hormones – female	2
Antispasmodics	1
Corticosteroids	1
Angiotensins	1
Nitrates	1
Inhalations	1
Contraceptives-Intra Uterine	1
Posterior pituitary hormones	1
Contraceptives - combined	1
Drugs for urinary retention	1
Anti-spasmodics	1
Urological Pain	1

Mean = 6.41, range 0-18, SD=3.64, SE= 0.35

b. Potential Side Effects of Medication Used

Responses	Frequency
Yes	16
No	2
Data Missing	84
TOTAL	102

6.Pain

a. Ability to express pain

Responses	Frequency
Yes	95
No	7
Don't Know	0
Data Missing	0
TOTAL	102

b. Frequent, occasional or periodical pain experienced

Responses	Frequency
Yes	67
No	32
Don't Know	3
Data Missing	0
TOTAL	102

7. Circulation & Breathing

a. Pulse

Responses	Frequency
Data Provided	42
Data Missing	60
TOTAL	102

b. Respiratory Rate

Responses	Frequency
Data Provided	32
Data Missing	70
TOTAL	102

c. Blood Pressure

Responses	Frequency
Normal	14
High	21
Low	6
Data Missing	61
TOTAL	102

d. Oedema

Responses	Frequency
Yes	9
No	93
Don't Know	0
Data Missing	0
TOTAL	102

e. Cyanosis

Responses	Frequency
Yes	0
No	102
Don't Know	0
Data Missing	0
TOTAL	102

f. Signs of cardio-pulmonary disorder

Responses	Frequency
Yes	1
No	101
Don't Know	0
Data Missing	0
TOTAL	102

g. Breathing difficulty, asthma, or a persistent troublesome cough

Responses	Frequency
Yes	12
No	90
Don't Know	0
Data Missing	0
TOTAL	102

h. Congenital or chronic circulatory or pulmonary disorder

Responses	Frequency
Yes	9
No	93
Don't Know	0
Data Missing	0
TOTAL	102

i. Varicose Veins

Responses	Frequency
Yes	2
No	98
Don't Know	2
Data Missing	0
TOTAL	102

8. Genito-Urinary System

a. Incontinent by day or night

Responses	Frequency
Yes	37
No	65
Don't Know	0
Data Missing	0
TOTAL	102

b. Pattern of incontinence changed recently

Responses	Frequency
Yes	6
No	96
Don't Know	0
Data Missing	0
TOTAL	102

c. Problems passing urine

Responses	Frequency
Yes	2
No	100
Don't Know	0
Data Missing	0
TOTAL	102

d. Abnormally colored or smelling urine

Responses	Frequency
Yes	2
No	96
Don't Know	3
Data Missing	1
TOTAL	102

9. Epilepsy

a. Any form of epilepsy

Responses	Frequency
Yes	41
No	60
Don't Know	1
Data Missing	0
TOTAL	102

b. Accurate record of seizures maintained

Responses	Frequency
Yes	41
No	0
Don't Know	0
Data Missing	0
TOTAL	41

c. Change in the frequency or pattern of seizures recently

Responses	Frequency
Yes	1
No	39
Don't Know	1
Data Missing	0
TOTAL	41

d. Receive anti-convulsant medication

Responses	Frequency
Yes	32
No	9
Don't Know	0
Data Missing	0
TOTAL	41

e. Medication require regular blood testing

Responses	Frequency
Yes	26
No	15
Don't Know	0
Data Missing	0
TOTAL	41

f. Staff fully aware of the potential side effects of the anti-convulsant medication

Responses	Frequency
Yes	34
No	7
Don't Know	0
Data Missing	0
TOTAL	41

10. Digestion and Elimination

a. Diet obviously deficient in any way

Responses	**Frequency**
Yes	15
No	97
Don't Know	0
Data Missing	0
TOTAL	102

b. 'Special' diet for any reason

Responses	**Frequency**
Yes	26
No	76
Don't Know	0
Data Missing	0
TOTAL	102

c. Drink adequate fluids

Responses	**Frequency**
Yes	92
No	13
Don't Know	1
Data Missing	0
TOTAL	102

d. Constipation or loose motions

Responses	**Frequency**
Yes	29
No	71
Don't Know	2
Data Missing	0
TOTAL	102

e. Abnormally coloured motions

Responses	Frequency
Yes	8
No	90
Don't Know	4
Data Missing	0
TOTAL	102

f. Frequent discomfort that might originate in the digestive system or bowel

Responses	Frequency
Yes	11
No	87
Don't Know	4
Data Missing	0
TOTAL	102

g. Chronic digestive condition

Responses	Frequency
Yes	16
No	84
Don't Know	2
Data Missing	0
TOTAL	102

h. Difficulty or reluctance to eat, or have any peculiar eating habits

Responses	Frequency
Yes	22
No	78
Don't Know	2
Data Missing	0
TOTAL	102

11. Skin

a. Any rash, irritation or itching

Responses	Frequency
Yes	30
No	72
Don't Know	0
Data Missing	0
TOTAL	102

b. Moles or other marks not present at the last examination, or which have changed

Responses	Frequency
Yes	7
No	94
Don't Know	1
Data Missing	0
TOTAL	102

c. Pressure areas that become inflamed

Responses	Frequency
Yes	4
No	96
Don't Know	2
Data Missing	0
TOTAL	102

d. Damaged or broken skin

Responses	Frequency
Yes	22
No	80
Don't Know	0
Data Missing	0
TOTAL	102

e. Chronic or long standing skin condition

Responses	Frequency
Yes	23
No	79
Don't Know	0
Data Missing	0
TOTAL	102

f. Offensive body odour or other personal hygiene problem

Responses	Frequency
Yes	12
No	90
Don't Know	0
Data Missing	0
TOTAL	102

12. Physique and Mobility

a. Permanently physically handicapped

Responses	Frequency
Yes	18
No	84
Don't Know	0
Data Missing	0
TOTAL	102

b. Gross motor activity and dexterity impaired

Responses	Frequency
Yes	27
No	75
Don't Know	0
Data Missing	0
TOTAL	102

c. Difficulty coordinating movement and/or hand-eye coordination

Responses	Frequency
Yes	26
No	76
Don't Know	0
Data Missing	0
TOTAL	102

d. Persistently poor posture, stooping or spinal curvatures

Responses	Frequency
Yes	27
No	75
Don't Know	0
Data Missing	0
TOTAL	102

e. Contracture problems

Responses	Frequency
Yes	4
No	97
Don't Know	1
Data Missing	0
TOTAL	102

f. Evidence of tremors, twitches or other uncontrolled movements

Responses	Frequency
Yes	31
No	72
Don't Know	0
Data Missing	0
TOTAL	102

g. Myoclonic spasms

Responses	Frequency
Yes	9
No	92
Don't Know	1
Data Missing	0
TOTAL	102

h. Loss of movement or pain on movement

Responses	Frequency
Yes	4
No	98
Don't Know	0
Data Missing	0
TOTAL	102

i. Muscle wasting

Responses	Frequency
Yes	9
No	93
Don't Know	0
Data Missing	0
TOTAL	102

j. Mobility or positioning aids

Responses	Frequency (Percentage)
Yes	18
No	84
Don't Know	0
Data Missing	0
TOTAL	102

13. Feet

a. Is there an obvious problem in relation to the shape of the feet

Responses	Frequency
Yes	16
No	85
Don't Know	1
Data Missing	0
TOTAL	102

b. Is there any evidence of skin problems on the feet or between the toes, any signs of itching or discomfort

Responses	Frequency
Yes	15
No	86
Don't Know	1
Data Missing	0
TOTAL	102

c. Toe nails thick, misshapen or abnormal

Responses	Frequency
Yes	11
No	84
Don't Know	7
Data Missing	0
TOTAL	102

d. Pain in the feet

Responses	Frequency
Yes	7
No	92
Don't Know	3
Data Missing	0
TOTAL	102

e. Chronic foot problem

Responses	Frequency
Yes	8
No	93
Don't Know	1
Data Missing	0
TOTAL	102

f. Is there any evidence of circulation problems to the feet

Responses	Frequency
Yes	32
No	69
Don't Know	1
Data Missing	0
TOTAL	102

14. Oral hygiene

a. Regular dental checks

Responses	Frequency
Yes	86
No	12
Don't Know	2
Data Missing	2
TOTAL	102

b. Does the client have any teeth

Responses	Frequency
Yes	95
No	5
Don't Know	2
Data Missing	1
TOTAL	102

c. Obvious problem with teeth or gums

Responses	Frequency
Yes	24
No	85
Don't Know	1
Data Missing	1
TOTAL	102

d. Difficulty chewing

Responses	Frequency
Yes	16
No	85
Don't Know	0
Data Missing	1
TOTAL	102

e. Persistently offensive breath

Responses	Frequency
Yes	19
No	82
Don't Know	0
Data Missing	1
TOTAL	102

f. Dribble excessively

Responses	Frequency
Yes	8
No	93
Don't Know	0
Data Missing	1
TOTAL	102

g. Chronic Mouth Condition

Responses	Frequency
Yes	3
No	98
Don't Know	0
Data Missing	1
TOTAL	102

h. Frequent mouth sores or ulcers

Responses	Frequency
Yes	2
No	99
Don't Know	0
Data Missing	1
TOTAL	102

i. Painful or sensitive teeth

Responses	Frequency
Yes	11
No	81
Don't Know	9
Data Missing	1
TOTAL	102

j. Dentures

Responses	Frequency
Yes	9
No	92
Don't Know	0
Data Missing	1
TOTAL	102

k. Dentures worn

Responses	Frequency
Yes	9
No	0
Don't Know	0
Data Missing	0
TOTAL	9

15. Eyes and Vision

a. Obvious eye/vision defect

Responses	Frequency
Yes	36
No	66
Don't Know	0
Data Missing	0
TOTAL	102

b. Obvious opacity of the eyes

Responses	Frequency
Yes	8
No	92
Don't Know	2
Data Missing	0
TOTAL	102

c. Behaviour that might suggest discomfort or other problem of the eyes

Responses	Frequency
Yes	10
No	92
Don't Know	0
Data Missing	0
TOTAL	102

d. Behaviour that suggests problems of vision

Responses	Frequency
Yes	10
No	90
Don't Know	2
Data Missing	0
TOTAL	102

e. Discomfort of eyelids

Responses	Frequency
Yes	3
No	99
Don't Know	0
Data Missing	0
TOTAL	102

f. Wear spectacles

Responses	Frequency
Yes	39
No	63
Don't Know	0
Data Missing	0
TOTAL	102

16. Ears and Hearing

a. Obvious ear problem

Responses	Frequency
Yes	12
No	90
Don't Know	0
Data Missing	0
TOTAL	102

b. Behaviour suggest a hearing problem

Responses	Frequency
Yes	10
No	92
Don't Know	0
Data Missing	0
TOTAL	102

c. History of ear problems

Responses	Frequency
Yes	17
No	83
Don't Know	2
Data Missing	0
TOTAL	102

d. Impacted or excess earwax

Responses	Frequency
Yes	20
No	80
Don't Know	2
Data Missing	0
TOTAL	102

e. Use of a hearing aid

Responses	Frequency
Yes	3
No	99
Don't Know	0
Data Missing	0
TOTAL	102

f. Balance problems

Responses	Frequency
Yes	15
No	86
Don't Know	1
Data Missing	0
TOTAL	102

17. Female Sexual Health

a. Breast Examination

Responses	Frequency
Yes	9
No	22
Don't Know	2
Data Missing	1
TOTAL	34

b. Cervical Smear

Responses	Frequency
Yes	12
No	20
Don't Know	2
Data Missing	0
TOTAL	34

c. Regular menstruation

Responses	Frequency
Yes	19
No	13
Don't Know	2
Data Missing	0
TOTAL	34

d. Physical or psychological problems associated with menstrual cycle

Responses	Frequency
Yes	19
No	13
Don't Know	2
Data Missing	0
TOTAL	34

e. Discomfort or itching of anus, perineum or genitals

Responses	Frequency
Yes	6
No	28
Don't Know	0
Data Missing	0
TOTAL	34

18. Male Sexual Health

a. Testicular/genital examination

Responses	Frequency
Yes	13
No	34
Don't Know	14
Data Missing	0
TOTAL	61

b. Dribble after passing urine

Responses	Frequency
Yes	3
No	45
Don't Know	13
Data Missing	0
TOTAL	61

c. Discomfort or itching of anus, perineum or genitals

Responses	Frequency
Yes	1
No	59
Don't Know	0
Data Missing	1
TOTAL	61

19. Sleep

a. Disturbed sleep pattern

Responses	Frequency
Yes	24
No	77
Don't Know	1
Data Missing	0
TOTAL	102

b. Stay awake much of the night

Responses	Frequency
Yes	13
No	89
Don't Know	0
Data Missing	0
TOTAL	102

c. Sleep much of the day

Responses	Frequency
Yes	23
No	78
Don't Know	1
Data Missing	0
TOTAL	102

d. Use of night sedation to assist sleep

Responses	Frequency
Yes	7
No	94
Don't Know	1
Data Missing	0
TOTAL	102

20. Mental Health

a. Frequent emotional distress

Responses	Frequency
Yes	32
No	68
Don't Know	1
Data Missing	1
TOTAL	102

b. Irrational mood swings

Responses	Frequency
Yes	44
No	57
Don't Know	1
Data Missing	0
TOTAL	102

c. Altered perceptions

Responses	Frequency
Yes	38
No	56
Don't Know	7
Data Missing	1
TOTAL	102

d. Irrational fears or anxieties

Responses	Frequency
Yes	32
No	67
Don't Know	2
Data Missing	1
TOTAL	102

e. Obsessional behaviours

Responses	Frequency
Yes	59
No	42
Don't Know	1
Data Missing	0
TOTAL	102

f. Psychosomatic disorders

Responses	Frequency
Yes	7
No	92
Don't Know	2
Data Missing	1
TOTAL	102

g. Frequent or periodic headaches

Responses	Frequency
Yes	12
No	83
Don't Know	6
Data Missing	1
TOTAL	102

21. Lifestyle Risks

a. Sufficient regular exercise

Responses	Frequency
Yes	29
No	70
Don't Know	2
Data Missing	1
TOTAL	102

b. Habits that pose a threat to health

i) Smoking

Responses	Frequency
Yes	**22**
10/day	2
20/day	11
30/day	6
40/day	0
50/day	2
60+/day	1
No	80
Don't Know	0
Data Missing	0
TOTAL	102

ii) Drinking alcohol

Responses	Frequency
Yes	8
No	92
Don't Know	2
Data Missing	0
TOTAL	102

iii) Illicit drug use

Responses	Frequency
Yes	1
No	101
Don't Know	0
Data Missing	0
TOTAL	101

d. Self injurious behaviour

Responses	Frequency
None	66
Hits Face	14
Bites	9
Hits Body	6
Scratches Face	5
Scratches Body	5
Inserts Objects Under Skin	4
Ligatures	3
Cuts Self	2
Pulls Hair	2
Burns Self	1
Anal Probing	1
Eats Soap	1
Vomits	1
Eats Cleaning Products	1
Strangulation	1
Pica	1
TOTAL	123

22.Stressors

Responses	Frequency
None	80
No access to money	7
New people, places, environment	5
Change to routine	4
Other service users	3
Anxiety	2
No access to tobacco	2
Friends & Family	2
Feeling Oppressed	2
Noise	2
Failing	1
Health appointments	1
Boredom	1
Crowds	1
Past Life Events	1
TOTAL	114

23. Other Health Issues (not included elsewhere)

Condition	Frequency
Psychosis	38
Depressive Disorder	33
Anxiety Disorders	27
Hypertension	25
Hypersensitivity	22
GORD	20
Hyperlipidaemia	20
GI Mobility Problem	18
Hypothyroidism	16
Eczema	15
Other GI	10
Schizotypal Disorders	10
Asthma	10
Movement Disorders	8
Type 2 Diabetes	8
Heart Disease	7
Ischaemic Heart Disease	7
Oesophageal Disorders	6
Osteoporosis	5
Dysphagia	5
Osteoarthritis	4
Spinal Cord Disorder	4
Mania	4
Dementia	4
Infectious Disease	4
Peripheral Valvular Disease	3
Glomerular Disease	3
Gastritis	3
Lung Disease	3
Skin Tumours	3

Anaemia	2
Vasculitis	2
Thrombosis	2
Cerebral Palsy	2
Valvular Disease	2
Congenital Heart Disease	2
Hydrocephalus	2
Peripheral Nerve Disease	2
Psoriasis	2
Rheumatoid Arthritis	2
Cardiac Failure	2
Mouth Ulcers	1
H. Pylori	1
Type 1 Diabetes	1
Gastrointestinal Cancer	1
Prostate Hypertrophy	1
Renal Failure	1
Migraine	1
Bullous Disease	1
Nail Infection	1
Cardiac Arrhythmias	1
Hypocalaemia	1

Range 0-11, mean =4.31

Information from the Health of the Nation Outcome Scales-Learning Disability (HoNOS-LD).

Item	0	1	2	3	4	No Data	TOTAL	Significant Problem
Behavioural Problems-directed at others	27	27	16	14	11	7	102	41
Behavioural Problems – directed at self	52	17	16	3	7	7	102	26
Other mental and behaviour problems	23	23	30	12	7	7	102	49
Attention & Concentration	30	19	11	28	7	7	102	49
Memory & Orientation	46	10	12	23	4	7	102	39
Communication – understanding	48	17	18	2	10	7	102	30
Communication-expression	31	30	13	11	10	7	102	34
Hallucinations & Delusions	62	13	9	8	3	7	102	20
Mood changes	44	25	19	7	4	7	102	30
Sleeping	47	25	8	13	2	7	102	23
Eating & Drinking	65	16	5	5	4	7	102	14
Physical Problems	64	11	5	5	10	7	102	20
Seizures	69	10	8	4	4	7	102	16
Activities of daily living-home	42	20	25	6	2	7	102	33
Activities of daily living-other	27	18	19	16	15	7	102	50
Self care	52	14	16	7	6	7	102	29
Relationships	41	27	17	5	5	7	102	27
Occupation & Activities	25	23	27	8	12	7	102	47

0=no problem; 1=minor problem, no action required; 2=mild problem but present; 3=moderately severe problem; 4=severe-very severe problem; significant problem = mild, moderate or severe

Information from the Reiss Screen

Reiss Sub-scales	Mean Scaled Scores (Range)	Frequency reaching clinical significance
Aggression	3.81 (0-14)	11
Autism	2.23 (0-10)	2
Psychosis	2.77 (0-15)	4
Paranoia	2.46 (0-11)	6
Depression (B)	2.49 (0-12)	6
Depression (P)	2.37 (0-15)	5
Avoidant	3.43 (0-32)	5
Other Maladaptive Behaviour	2.53 (0-14)	2

Information from the Glasgow Depression Scale (GDS)

Outcome	Frequency
Below Clinical Cutoff	47
Above Clinical Cutoff	11
Not Completed in Best Interests	6
No Data	38
TOTAL	102

Information from the Behaviour Problem Inventory (BPI)

ITEM	Behaviour Score (mean and range)	Frequency reaching clinical significance
Self-biting	2.35 (0-54)	8
Head hitting with hand or other body part	1.97 (0-54)	6
Body hitting (except for the head) with own hand or with any other body part	0.90 (0-18)	2
Self-scratching	2.79 (0-36)	11
Pica	0.63 (0-27)	2
Inserting inappropriate objects in nose, ears, anus, etc.)	0.82 (0-36)	3
Hair pulling (tearing out patches of hair)	0.18 (0-6)	0
Teeth grinding (evidence of ground teeth)	1.45 (0-36)	5
TOTAL SELF-INJURIOUS BEHAVIOUR SCORE	11.08 (0-95)	34

ITEM	Total Behaviour Score (mean and range)	Frequency reaching clinical significance
Rocking back and forth, repetitive body movements	4.83 (0-63)	12
Sniffing objects, own body	1.38 (0-45)	4
Waving or shaking arms	1.89 (0-54)	8
Manipulating (e.g., twirling, spinning) objects repeatedly	2.03 (0-63)	5
Repetitive hand and/or finger movements	3.92 (0-73)	10
Yelling and screaming	5.24 (0-45)	20
Pacing, jumping, bouncing, running	6.30 (0-63)	15
Rubbing self	2.66 (0-45)	12
Gazing at hands or objects	1.88 (0-54)	7
Bizarre body postures	1.46 (0-45)	5
Clapping hands	1.28 (0-54)	6
Grimacing	2.62 (0-54)	14
TOTAL STEREOTYPED BEHAVIOUR SCORE	36.44 (0-342)	51

ITEM	Total Behaviour Score (mean and range)	Frequency reaching clinical significance
Hitting others	4.01 (0-45)	17
Kicking others	1.98 (0-30)	7
Pushing others	2.20 (0-27)	9
Biting others	0.90 (0-27)	5
Grabbing and pulling others	2.74 (0-63)	9
Scratching others	2.22 (0-54)	8
Pinching others	1.87 (0-45)	8
Verbally abusive with others	4.66 (0-27)	22
Destroying things (e.g., rips clothes, throws chairs, smashes table)	3.26 (0-36)	17
Bullying - being mean or cruel (e.g., grabbing toys or food from others)	3.01 (0-54)	13
TOTAL AGGRESSIVE OR DESTRUCTIVE BEHAVIOUR SCORE	26.97 (0-273)	44

Information from the International Physical Activity Questionnaire (proxy IPAQ)

Level of Physical Activity	Frequency
None[1]	1
Low[2]	54
Moderate[3]	42
High[4]	5
TOTAL	102

[1] 0 activity

[2] <5 days walking/moderate PA, <30mins/day

[3] 5+ days walking/moderate PA, 30mins/day

[4] 7 days walking/moderate/hard PA, 30mins/day

Appendix U
Healthy Lifestyle Project Protocol

<u>Healthy Lifestyle Project (HLP): Protocol</u>

<u>Intervention (HLP) Group</u>

1. Residential service to invite 30 participants, who were classed as overweight or obese or morbidly during residential service's latest health to take part in HLP project. **Note if clients are now the desirable weight for their height (BMI), the invitation will be withdrawn**.

2. Provide staff and clients with information sheets detailing the intervention and the processes involved.

3. Assess capacity to consent, using a functional assessment of capacity.

4. If potential participants have capacity, gain informed consent.

5. Assign participants a participant number.

6. Pre-intervention (baseline) data collection, to be completed by residential service's staff:

   a. Weight (kg), BMI and % of body fat
      i. using same set of scales
      ii. Record on HLP data collection form

   b. Waist and hip circumference (cm)
      i. Record on HLP data collection form

   c. Physical activity
      1. using IPAQ-proxy respondent version
      2. using accelerometer data

   d. Diet
      i. Dietary assessment DHQ
         1. Fruit and vegetable consumption
         2. Healthy eating habits

7. <u>Intervention (to be run by residential service's staff)</u>

   a. Diet
      i. To include
         1. Calorie controlled diet –reduction of 500 kcal/day
            a. Dietary prescription from qualified & accredited dietician employed by residential service
         2. Increase fruit and vegetable consumption
         3. Promote healthy food choices
      ii. Qualified and accredited dietician employed by residential service to

1. Complete dietary assessments on all participants

2. Develop personalised "Dietary Prescriptions" aiming to reduce calorific intake by 500 kcal/day

3. Develop staff training on the benefits of healthy eating, basic nutritional information, and to develop healthy eating menus in collaboration with chefs employed by residential service's in their hospital settings.

b. Physical Activity

   i. Decrease sedentary behaviour in the home

      1. participants to spend more time "moving" when at home e.g. by doing more household chores, fewer activities which involve sitting still (watching TV, etc).

   ii. Increasing physical activity levels

      1. All participants to reach NICE/WHO guidelines for 30 minutes of moderate intensity physical activity on 5 or more days of the week (minimum)

      2. Physical activities will need to be community based and activities coordinators to be responsible for increasing physical activity levels

         • Arrange "taster sessions" for different physical activities

   iii. Staff to be educated

      1. benefits of physical activity

      2. activities co-ordinators to be given lists of physical activity classes/sessions which are locally based

      3. Dietician to educate staff on healthy diet

c. Health Education/Promotion

   i. Based on Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities (Marks, Sisirak, & Heller)

   ii. HLP group to receive weekly group based sessions to go through the "lessons", using handouts available from the curriculum.

      1. All residential units for HLP group will receive a copy of the curriculum.

      2. Participants will attend the weekly sessions with a member of support staff (same member of staff each week if possible)

         • Will allow staff members to

         o support participants to complete weekly homework, to complete handouts in sessions, support participants outside of sessions

         o benefit from increased knowledge from the curriculum- thus acting as additional staff training.

    d. Behaviour modification

      i. To include Behaviour Modification – self-monitoring, stimulus control, goal setting, slowing rate of eating, social support, problem solving, assertiveness, cognitive restructuring, reinforcement of change, relapse prevention, strategies for dealing with weight gains

      ii. Based on sessions in Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities (Marks, Sisirak, & Heller).

        1. Where appropriate sessions aren't provided in the curriculum, these sessions will be developed and delivered by residential service's psychologists.

10. Weekly Data Collection to be completed by residential service's staff

  a. Weight (kg), BMI and % of body fat

    i. using same set of scales

    ii. Record on HLP data collection form

  b. Waist and hip circumference (cm)

    i. Record on HLP data collection form

  c. Attendance in weekly sessions

    ii. Record on HLP data collection form

11. Weekly sessions will include the reinforcement of positive results.

  a. Participants will be told of their weight loss

  b. Results (number of pounds or kilos lost) will be recorded on a chart

  c. Certificates given for weight loss

12. Weekly sessions will also provide encouragement for people who haven't lost weight.

13. Post-intervention data collection to be completed by residential service's staff:

  a. Weight (kg), BMI and % of body fat

    i. using same set of scales

    ii. Record on HLP data collection form

  b. Waist and hip circumference (cm)

    i. Record on HLP data collection form

     c. Physical activity

          1. using IPAQ-proxy respondent version

          2. using accelerometer data

     d. Diet

        i. Dietary assessment -DHQ

14. Maintenance Phase of HLP Intervention

     a. Monthly HLP group sessions following the same structure as above

        i. Emphasis on maintaining a healthy weight through diet and physical activity

        ii. How to prevent weight gain

        iii. Emphasis on behaviour modification techniques

          1. Setting goals for physical activity and diet

15. 3 month follow-up data collection (3 months after end of intervention phase) to be completed by residential service's staff:

     a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

     b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

     c. Physical activity

          1. using IPAQ-proxy respondent version

          2. using accelerometer data

     d. Diet

        i. Dietary assessment -DHQ

16. 6 month follow-up data collection (6 months after end of intervention phase) to be completed by residential service's staff:

     a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

     b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

     c. Physical activity

          1. using IPAQ-proxy respondent version

          2. using accelerometer data

     d. Diet

        i. Dietary assessment -DHQ

17. 12 month follow-up data collection (12 months after end of intervention phase) to be completed by residential service's staff:

    a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

    b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

    c. Physical activity

        1. using IPAQ-proxy respondent version

        2. using accelerometer data

    d. Diet

        i. Dietary assessment -DHQ

Waiting list Control (WLC) Group

1. Residential service to invite 30 participants, who were classed as overweight or obese or morbidly during residential service's latest health checks, to take part in HLP on waiting list basis

2. Provide staff and clients with information sheets detailing the intervention and the processes involved.

3. Assess capacity to consent, using a functional assessment of capacity.

4. If potential participants have capacity, gain informed consent.

5. Assign participants a participant number.

6. Pre-intervention (baseline) data collection to be completed by residential service's staff:

    a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

    b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

    c. Physical activity

        1. using IPAQ-proxy respondent version

        2. using accelerometer data

    d. Diet

        i. Dietary assessment -DHQ

        ii. Fruit and vegetable consumption

        iii. healthy eating habits

7. <u>Intervention</u>

    a. Health Education/Promotion book to be provided to each residential unit acting as WLC group

8. Post-intervention data collection (same time as HLP post-intervention data collection) to be completed by residential service's staff:

    a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

    b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

    c. Physical activity

        1. using IPAQ-proxy respondent version

        2. using accelerometer data

    d. Diet

        i. Dietary assessment -DHQ

9. 3 month follow-up data collection (3 months after end of intervention phase- same time as HLP post-intervention data collection) to be completed by residential service's staff:

    a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

    b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

    c. Physical activity

        1. using IPAQ-proxy respondent version

        2. using accelerometer data

    d. Diet

        i. Dietary assessment -DHQ

10. 6 month follow-up data collection (6 months after end of intervention phase- same time as HLP post-intervention data collection) to be completed by residential service's staff:

    a. Weight (kg), BMI and % of body fat

        i. using same set of scales

        ii. Record on HLP data collection form

    b. Waist and hip circumference (cm)

        i. Record on HLP data collection form

    c. Physical activity

      1. using IPAQ-proxy respondent version

      2. using accelerometer data

  d. Diet

    i. Dietary assessment -DHQ

11. 12 month follow-up data collection (12 months after end of intervention phase- same time as HLP post-intervention data collection) to be completed by residential service's staff:

  a. Weight (kg), BMI and % of body fat

    i. using same set of scales

    ii. Record on HLP data collection form

  b. Waist and hip circumference (cm)

    i. Record on HLP data collection form

  c. Physical activity

      1. using IPAQ-proxy respondent version

      2. using accelerometer data

  d. Diet

    i. Dietary assessment -DHQ

NOTE – if the HLP is an effective method for weight loss in adults with ID, the WLC group will be moved to the HLP phase sooner

Content of Health Matters: *The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities* (Marks, Sisirak, & Heller)

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- Using the Curriculum to Start Your Exercise and Nutrition Health Education Program
- Tips for Starting a Health Promotion Program
- Teaching Approaches
- Additional Considerations
- Evaluating Changes in Participants
- Summary

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- Lesson 2: What Is Physical Activity?
- Lesson 3: Things to Do Before We Exercise
- Lesson 4: Exercise Is Good
- Lesson 5: What Do Different Exercises Do for My Body?
- Lesson 6: Good Nutrition
- Lesson 7: How Much Energy Does It Take?
- Lesson 8: Healthy Choices/Self-Advocacy

Unit 2: Changing Lifestyle: What Are the Things We Do?

- Lesson 9: What Do I Think of Me?
- Lesson 10: What Is My Heart Rate?
- Lesson 11: What Is My Blood Pressure?
- Lesson 12: What Exercises Do I Like in My Community?
- Lesson 13: What Are Good and Bad Influences?
- Lesson 14: Am I Drinking Enough Water?
- Lesson 15: What Foods Do I Like to Eat?
- Lesson 16: How About My Medications and Exercise?

Unit 3: Making Lifestyle Changes: Setting Goals

- Lesson 17: Things to Remember When Exercising
- Lesson 18: Community Fitness Center Visit: Using Exercise Machines Safely

- Lesson 19: How to Breathe When We Exercise

- Lesson 20: Why Do We Clean Equipment?
- Lesson 21: Nutrients We Need
- Lesson 22: Exercise Plans: Becoming More Active
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Unit 4: Lifestyle Changes: Doing My Program

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- Lesson 25: What Is Good Pain and Bad Pain?
- Lesson 26: How Does Sleep Affect Physical Activity?
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- Lesson 29: Am I Meeting My Goals?
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Unit 5: New Lifestyle: Keeping My Program Going

- Lesson 31: Restructuring My Environment
- Lesson 32: Getting Back on Track
- Lesson 33: Creating an Exercise Video
- Lesson 34: Reviewing Our Goals to Stay Connected
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Section III: Appendixes

Description of the Appendixes

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- Appendix B: Glossary
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- Appendix D: Universal Design for Health Promotion: Developing Creative Solutions for People Who Have Severe/Profound Intellectual Disabilities and a Variety of Physical Disabilities
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