

# **Dietary intake practices of adults with intellectual disability in a controlled care centre environment**

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*This research is dedicated to my autistic son, Franco, one of a large group of differently abled people that need our love, support and respect.*

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## ABSTRACT

### Background and aim

Globally, inadequate nutrition and consequently, obesity is highly prevalent among adults with intellectual disability. Overweight and obesity leads to an increased risk for the development of non-communicable diseases, such as diabetes mellitus, cardiovascular diseases, and cancer. Secondary conditions may result in further disability, pain, loss of employment, and depression in adults with intellectual disability. Dietary intake studies concerning the intellectually disabled population have revealed insufficient fibre, fruits and vegetables, and excessive total fat, saturated fat, and sodium consumption. Unfortunately, research is lacking in this population, especially in South Africa. Therefore, it is necessary to assess the dietary intake practices of adults with intellectual disability in a controlled, care centre environment in South Africa with the future aim of compiling intervention programmes to improve the overall quality of life in this population.

### Methods

The researcher used qualitative and quantitative methods to collect data. Quantitatively demographic, anthropometric, and dietary data were recorded of 66 adults (18-40 years) with intellectual disability at two care centres. The measuring instrument used for the dietary intake was a three-day food wastage study on different days, within three weeks. All snacks that the adults with intellectual disability bought at the snack shop and supermarket during the three days, were recorded. The adults with intellectual disability received three meals per day with one snack at 10:00 prepared at a central kitchen from a fixed menu. Qualitative data on the dietary intake practices during meals, between meals, and other eating occasions were recorded *via* three focus group discussions with caregiver staff who know the adults with intellectual disability well.

### Results

The mean body mass index of the men (27.3) and women (33.1) with intellectual disability in this study indicated overweight and obesity respectively. The dietary diversity and quality of the adults with intellectual disability's diet, and the menus at the care centres were low. Dietary intake was compared to the Food Based Dietary Intake Guidelines of South Africa. Fibre, carbohydrate, fruit, and vegetable dietary intake were lower than recommendations. In contrast, sodium, total fat, saturated fat, and added sugar intakes were higher than recommendations. The most popular snacks and drinks consumed by the adults with intellectual disability in this study population were salted crisps and carbonated drinks. During the focus group discussions, the caregivers complained about high-fat cooking methods used by the cooks, and therefore,

expressed a need for cooking skills training. Additionally, the caregivers expressed a need for more variety in the menus, healthier snacks, and improved communication between them.

**Conclusion**

The dietary intake of the adults with intellectual disability was not according to recommendations. The following observations translate into recommendations made in order to improve the overall quality of dietary intake of the adults with intellectual disabilities. There is a need at the centres for training in cooking skills, menu planning, and basic nutrition. The adults with intellectual disability need guidance and training in good nutrition and healthy food choices. Continuous, professional input from dietitians is recommended for the compilation of menus, as well as the training of both the staff and the adults with intellectual disability.

**Keywords:** intellectual disability, dietary intake, dietary practices, controlled environment, dietary quality, dietary diversity

## OPSOMMING

### Doel

Navorsing wêreldwyd in volwassenes met 'n intellektuele gestremdheid dui op 'n lae kwaliteit dieetinname met 'n gevolglike hoë voorkoms van oorgewig en vetsug. Oorgewig en vetsug verhoog die risiko vir die ontwikkeling van leefstyl siektes soos diabetes mellitus, kardiovaskulêre siektes en kanker. Hierdie sekondêre toestande kan weer lei tot verdere gestremdheid en pyn met 'n gevolglike verlies van werk en inkomste asook depressie. Dieetinname studies in volwassenes met intellektuele gestremdheid dui op onvoldoende vesel, vrugte en groente inname asook 'n oormatige inname van totale vet, versadigde vet en natrium. Ongelukkig is daar 'n tekort in navorsing in die populasie, veral in Suid-Afrika. Gevolglik is daar 'n behoefte vir navorsing in dieet praktyke wat gevolg word deur volwassenes met 'n intellektuele gestremdheid wat in 'n kontroleerde omgewing in sorgsentrums in Suid-Afrika gehuisves word. Die uiteindelige doel is om intervensie programme op te stel om die algehele lewenskwaliteit van die populasie te verbeter.

### Metode

Die navorser het kwantitatiewe en kwalitatiewe metodes gebruik om data van 66 intellektueel gestremde volwassenes van ouderdomme 18 tot 40 jaar in twee sorgsentrums in Suid-Afrika in te samel. Kwantitatief is demografiese, antropometriese en dieetinname data ingesamel. 'n Drie dag voedselkwistingstudie is uitgevoer om dieetinname te meet. Al die versnapperinge wat die deelnemers by die snoepwinkel en supermark gekoop het is ook aangeteken. Albei sorgsentrums voorsien drie maaltye, voorberei in 'n sentrale kombuis, met 'n 10:00 versnappering aan die gestremde inwoners. Kwalitatiewe data is ingesamel deur middel van drie fokusgroep besprekings wat gehou is met versorgers wat die inwonende volwassenes met 'n intellektuele gestremdheid goed ken.

### Resultate

Die gemiddelde ligaamsmassa indeks van die mans (27.3) en vrouens (33.1), met 'n intellektuele gestremdheid, dui onderskeidelik op oorgewig en obesiteit. Daar is gevind dat die diversiteit en kwaliteit van die spyskaarte en dieetinname van die volwassenes met 'n intellektuele gestremdheid laag is. Volgens die voedselgebaseerde dieetriglyne van Suid-Afrika het die inwoners van die twee sorgsentrums 'n onvoldoende inname van koolhidrate, groente en vrugte en vesel getoon. In teenstelling hiermee was die inname van totale vet, versadigde vette en toegevoegde suiker te hoog. Die mees gewilde versnapperinge was aartappelskyfies en gaskoeldranke. Tydens die fokusgroep besprekings het die versorgers hul ontevredenheid uitgespreek oor die hoë vetinhoud van sommige geregte en verkeerde kookmetodes wat gevolg

word deur die kokke. Daarbenemens was is daar 'n behoefte aan 'n meer diverse spyskaart, gesonde versnapperinge en verbeterde kommunikasie tussen die versorgers.

### **Gevolgtrekking**

Die dieetname van die volwassenes met 'n intellektuele gestremdheid in hierdie studie populasie het nie voldoen aan die aanbevelings nie. Die versorgers by die sentrums benodig opleiding in kookvaardighede, spyskaartbeplanning en basiese voeding om sodoende die kwaliteit en diversiteit van die spyskaart en dieetname te verbeter. Die volwassenes met intellektuele gestremdheid benodig leiding en opleiding in goeie voeding en gesonde voedselkeuses. Deurlopende betrokkenheid en insette van dieetkundiges in die opstel van spyskaarte, opleiding van personeel en die intellektueel gestremde volwassenes word aanbeveel.

**Sleutelwoorde:** Intellektueel gestremdheid, dieetname, dieet praktyke, gekontroleerde omgewing, dieet kwaliteit, dieet diversiteit.

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**LIST OF ABBREVIATIONS**

<b>AAIDD</b>	American Association of Intellectual and Developmental Disabilities
<b>AWID</b>	Adults with intellectual disability
<b>BCTs</b>	Behavioral change techniques
<b>BMI</b>	Body Mass Index
<b>CHO</b>	Carbohydrate
<b>CVA</b>	Cerebrovascular Accident
<b>CVD</b>	Cardiovascular Disease
<b>DDS</b>	Dietary Diversity Score
<b>DM</b>	Diabetes mellitus
<b>DQI</b>	Dietary Quality Index
<b>DQI-R</b>	Dietary Quality Index Revised
<b>DS</b>	Downs syndrome
<b>ED</b>	Eating disorder
<b>EI</b>	Energy intake
<b>FA</b>	Fatty acid
<b>FBDGs</b>	Food Based Dietary Guidelines
<b>GCWMS</b>	Glasgow & Clyde Weight Management Service
<b>GP</b>	General practitioner
<b>HREC</b>	Human Research Ethics Committee
<b>ID</b>	Intellectual Disability
<b>MCIs</b>	Multi-component interventions
<b>MUFA</b>	Monounsaturated fatty acid
<b>NA</b>	Not applicable
<b>NCDs</b>	Non-Communicable Diseases
<b>NHS</b>	National health service
<b>NWU</b>	North West University
<b>OSA</b>	Obstructive sleep apnoea
<b>PUFA</b>	Polyunsaturated fatty acid
<b>RCT</b>	Randomised controlled trial
<b>RDA</b>	Recommended daily allowance
<b>SA</b>	South Africa
<b>SADHS</b>	South African Demographic and Health Survey
<b>SAMRC</b>	South African Medical Research Council
<b>SFA</b>	Saturated fatty acid

## LIST OF ABBREVIATIONS

<b>SSBs</b>	Sugar sweetened beverages
<b>T1DM</b>	Type 1 diabetes mellitus
<b>T2DM</b>	Type 2 diabetes mellitus
<b>TFA</b>	Trans fatty acid
<b>UK</b>	United Kingdom
<b>USA</b>	United States of America
<b>WHO</b>	World Health Organization

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## CHAPTER 1: INTRODUCTION

This mini-dissertation investigates the dietary intake practices of adults with intellectual disability (AWID) in a controlled, care centre environment. Chapter 1 will provide an introduction of this work, present the research question, aim and hypothesis, as well as an explanation of the layout of the dissertation.

### 1.1 Background and motivation

Intellectual disability starts before the age of 18 years, and is distinguished by noteworthy limitations in brain function (learning, reasoning, and problem solving) and limitations in the ability to adapt behaviour (conceptual, social, and practical skills) (AAIDD, 2013). Synonyms used for ID in existing literature are cognitive disability, global developmental delay, mental retardation, and learning disability. In a meta-analysis of 52 worldwide studies, it was reported that approximately 10 persons in 1000 (or 1%) are intellectually disabled. Moreover, prevalence rates in low- and middle-income countries were the highest reported (Maulik *et al.*, 2011:419). Researchers have indicated that possible reasons for higher prevalence rates of ID in Africa are poverty, poor nutrition, and limited health services (Adnams, 2010:437; Njenga, 2009:457; McKenzie *et al.*, 2013:481). This is cause for concern because these countries also have limited resources to manage ID (Maulik *et al.*, 2011:419). People with ID in SA are among the poorest and most vulnerable (Adnams, 2010:436).

Globally, a current lack in extensive studies on the dietary practices of AWID is apparent (Adolfsson *et al.*, 2008:2; Ptomey. *et al.*, 2013:625). The researcher has identified a few studies that assess the nutritional intake of AWID (Adolfsson *et al.*, 2008:1; Bertoli *et al.*, 2006:100; Braunschweig *et al.*, 2004:186; Bhaumik *et al.*, 2008:287; Cunningham *et al.*, 1990:3; Draheim *et al.*, 2007:392; Hsieh *et al.*, 2014:851; McGuire *et al.*, 2007:497; Ptomey. *et al.*, 2013:625). Most of these studies were conducted in community settings in Italy, Sweden, Australia, Ireland, and the USA. Only one published dietary intake study on AWID in SA was found. The aforementioned study took place in a long-stay hospital setting in Cape Town, SA, and much has changed since its publication in 2000 (Molteno *et al.*, 2000:35) where AWID have been moved to care centres in the community (Foskett, 2014:19).

During the last few decades of the previous century, AWID have been moved from controlled environments (such as institutions and long-stay hospitals) to community settings (Humphries *et al.*, 2009:166). This move gave the AWID more freedom of choice, which had a greater impact on those living independently (Bhaumik *et al.*, 2008:287). Furthermore, AWID suffer from malnutrition (especially over nutrition) (Franssen *et al.*, 2011:239; Humphries *et al.*, 2009:163;

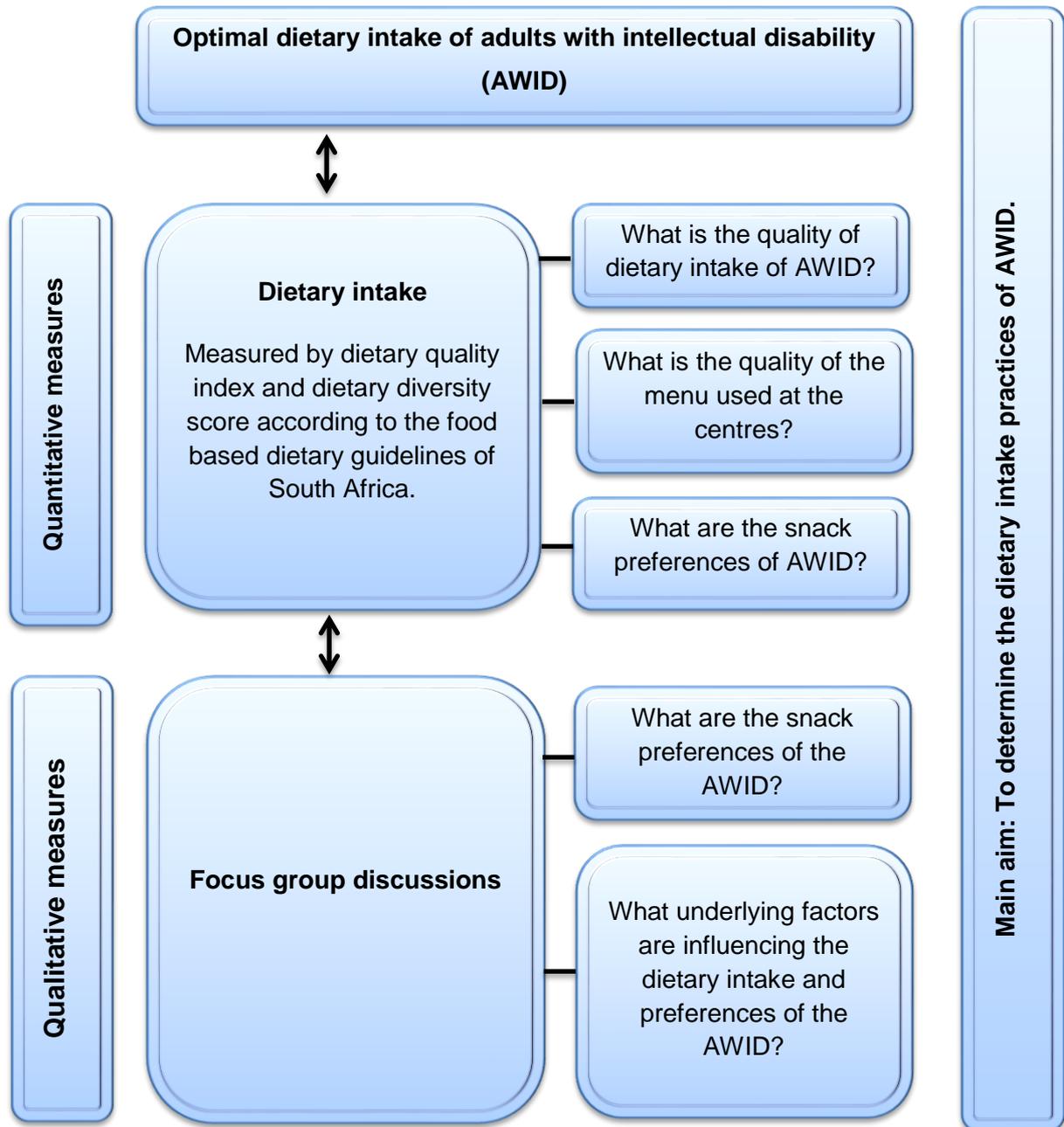
Tsai *et al.*, 2011:3296). In spite of more than sufficient energy intake, their dietary intake lacks quality to ensure good health and prevention of illness (Tanumihardjo *et al.*, 2007:1966). Moreover, AWID are prone to follow a sedentary lifestyle and are physically inactive (Bhaumik *et al.*, 2008:287; Emerson, 2011:155; Ferraro *et al.*, 2002:834; Lakdawalla *et al.*, 2004:168; Melville *et al.*, 2005:125; Rimmer *et al.*, 2010:2). This is evident from the increased prevalence rates of obesity in AWID (Melville *et al.*, 2008:425; Hsieh *et al.*, 2014:851). Obesity elevates the AWIDs' risk of developing non-communicable diseases (NCDs) such as diabetes mellitus (DM), cardiovascular disease (CVD), hypertension, stroke, and certain cancers (Nguyen & Lau, 2012:326). In fact, the prevalence of NCDs associated with obesity is more common among AWID (Carmeli *et al.*, 2004:180; Rimmer *et al.*, 2010:1; Van de Louw *et al.*, 2009:78). Malnutrition needs to be addressed to lower the risk for the development of overweight and obesity (Swinburn *et al.*, 2011:811) and therefore, the need for improving the diet quality of AWID is paramount (Ptomey & Wittenbrook 2015:593; WHO, 2000). Adults with ID generally have an insufficient intake of fruit and vegetables, whole grains, and foods containing omega-3 fatty acids (Bertoli *et al.*, 2006:100; Rimmer *et al.*, 2010:1). Furthermore, individuals with ID have a high intake in sodium, saturated fatty acids (SFAs), trans-fatty acids (TFAs), and refined carbohydrates (CHO) (Adolfsson *et al.*, 2010:259; Humphries *et al.*, 2004:517; Ptomey. *et al.*, 2013:626).

Although there is a dire need in research in all areas of disability in SA (Adnams, 2010:436), this study focuses on one of the most basic needs of man – optimal nutrition. In order to compile successful interventions regarding the dietary intake in AWID, more knowledge on the dietary intake practices and eating preferences are needed (Humphries *et al.*, 2009:163).

In SA, the move from controlled environments to community settings took place from 1997. Currently, it appears as if most of the AWID reside in the community with family (which is in line with other low- to middle-income countries) with less in residential settings (care centres) (McKenzie *et al.*, 2013:481). In SA, there is an overall paucity of information and services of AWID (Adnams, 2010:436; Foskett, 2014:19; McKenzie *et al.*, 2013:481; McKenzie & McConkey, 2016:531). Although most of the AWID in SA are living with families in the community, this study will focus on the controlled environment in care centres, and will be the first of its' kind in SA.

The question that this study will aim to answer is: “*What are the dietary intake practices of AWID in a controlled environment in SA?*” The outcome of this research may steer researchers, dietitians, and nutritionists to conduct further research and/or to develop effective dietary interventions for the prevention and management of overweight and obesity in AWID in care centres in SA. Figure 1.1 presents the conceptual framework of this research study with

underlying questions regarding the dietary intake of the AWID in the controlled care centre environment.



AWID, adults with intellectual disability

Figure 1-1: Conceptual framework of this research study

## **1.2 Title of the mini-dissertation**

Dietary intake practices of adults with intellectual disability in a controlled care centre environment.

## **1.3 Problem statement**

People with ID are a vulnerable group with higher prevalence of overweight and obesity than the general population (Grondhuis & Aman, 2014:787; Maiano, 2011:189; Melville *et al.*, 2008:425; Hsieh *et al.*, 2014:851). Research has shown that AWID are more prone to NCDs associated with obesity, for example type 2 diabetes mellitus (T2DM), CVD, and metabolic syndrome (Carmeli *et al.*, 2004:180; Rimmer *et al.*, 2010:1; Van de Louw *et al.*, 2009:78). Conditions secondary to obesity may result in pain, lethargy, depression, and social detachment. The result may be unemployment and/or loss of productivity, and decreased performance (Rimmer *et al.*, 2010:1) and, ultimately, a decrease in quality of life (Krahn & Fox, 2014:431).

The researcher is personally involved with AWID and is a registered dietitian, consulting both AWID and children with ID and their families. Through these experiences, it has come to the researcher's attention that AWID are more likely to make unhealthy food choices even under the supervision of adults without a disability. Therefore, this study will provide the researcher with dietary intake data and the underlying factors affecting their dietary intake. In addition, this increased knowledge will be in a South African context, where a paucity of data renders this population invisible (Adnams, 2010:436). Consequently, dietitians and nutritionists can plan and implement the necessary interventions to improve the overall health of AWID.

## **1.4 Purpose statement**

There is a need for successful intervention programmes to reach and maintain healthy weight in individuals with ID (Beeken *et al.*, 2013:2; Krahn & Fox, 2014:431). Scientifically observed data regarding the dietary intake and preferences of individuals with ID will be useful in developing these programmes in care centres. To the knowledge of the researcher, only one study assessed the dietary intake of AWID in 2000 in a long-stay hospital setting in Cape Town (Molteno *et al.*, 2000:35). Since residential facilities for AWID in SA differ from those in the USA and the United Kingdom (UK), the dietary intake in South African care centres need investigation. Therefore, knowledge on the dietary intake practices of AWID in SA will be very useful in order to guide and advise residential facilities in SA. Moreover, knowledge on dietary intake practices in AWID in SA will form a valuable basis for further research in this neglected

population. Successful intervention will prevent further disability and increased medical costs. Through intervention, AWID will have an improved quality of life.

## **1.5 Research aim and objectives**

The main aim of this study is to determine the dietary intake practices of people with ID in a controlled, care centre environment.

### **1.5.1 Specific objectives**

The following objectives address the main aim:

- assess the dietary intake of AWID in two South African care centres;
- determine the food preference of AWID in two South African care centres; and
- determine the underlying factors that have an influence on the dietary intake and preferences of AWID.

### **1.5.2 Hypotheses to be tested**

The following are hypothesised in the context of this study:

- the dietary intake of AWID does not measure up to the Food Based Dietary Guidelines (FBDGs) of SA;
- snack preferences of AWID are less healthy;
- the menu at the care centres are not optimal and influence AWIDs' diet quality and diversity; and
- the health care workers have little say to help guide AWID towards healthier food choices.

## **1.6 Methods and procedures**

The researcher followed a mixed-methods study design with quantitative and qualitative components (Leech & Onwuegbuzie, 2009:265; Onwuegbuzie *et al.*, 2009:1). A variety of databases (such as Google Scholar, One Search, Science Direct, Medline, Sabinet, and Ebscohost) were consulted to acquire background knowledge on AWID, NCDs, risk factors, dietary intake, and the FBDGs. This appraisal of the literature provided a platform for the compilation of the research questions, aim, and objectives of this study. A literature review followed to conduct an investigation concerning the impact of obesity on the health and wellness of AWID, and the role of the dietary intake in the development and treatment of obesity in AWID.

The researcher obtained ethical permission from the Human Research Ethics Committee (HREC) (NWU-00070-16-S1) of the Faculty of Health Sciences of the NWU for this study before the first participants were recruited. The one assent and two consent forms for the study participants have been included in Annexure A. The measuring instrument used in the qualitative data collection phase was a three-day food wastage study. The quantitative data was collected through three focus group discussions with the staff members working closely with the AWID until satiety was reached (see interview schedule in Annexure B). A statistical consultant at the North-West University was conferred with before and after the study to assist with the statistical analysis of the study.

### 1.7 Research team and contribution

**Table 1-1: Research team**

<b>Team member</b>	<b>Institution</b>	<b>Contribution</b>
<b>Mrs S. J. Dreyer</b>	MSc student at Centre of Excellence for Nutrition, NWU, Potchefstroom Campus	Primary researcher
<b>Dr C. R. Botha-Ravyse</b>	Extraordinary Senior Lecturer, School of Physiology, Nutrition and Consumer Sciences, NWU, Potchefstroom Campus	Supervisor and general project advisor, funding
<b>Prof. S. M. Hanekom</b>	Director at School of Physiology, Nutrition and Consumer Sciences, NWU, Potchefstroom Campus	Co-supervisor, project advisor, and expert on food wastage studies

*NWU, North-West University*

## 1.8 Chapter division of this mini-dissertation

This mini-dissertation is written in article format. It has been edited by an accredited language editor. See Annexure C for the certificate of editing. The guidelines in the postgraduate manual of the North-West University (NWU) are applied to all technical aspects (font Arial, size 11) except for Chapter 3. In Chapter 3 the authors' guidelines for the "American Journal on Intellectual and Developmental Disability" have been used (font New Times Roman, size 12) and are presented in Annexure, D. The research study consists of four chapters, which are:

**Chapter 1** the introductory chapter, presents the introduction; background and substantiation; research question; purpose; and objectives for this research study.

**Chapter 2** provides a literature review on the impact of obesity in AWID; risk factors for the development of obesity in this population; and finally a look at intervention programmes described in the literature.

**Chapter 3** presents an article titled "*Dietary practices in adults with intellectual disability in a controlled care centre environment*". The article is a mixed-methods descriptive study where quantitative and qualitative data were used to describe the dietary intake practices of adults in two care centres for AWID in South Africa. A concurrent triangulation strategy was followed. Proof of submission is presented in Annexure E.

**Chapter 4** consists of the summary; conclusions; recommendations; limitations; and implications of the research study.

The reference style is in the NWU Harvard style for Chapters 1, 2 and 4. Chapter 3 follows the referencing style for the "American Journal on Intellectual and Developmental Disability". The combined bibliography is presented at the end of the document also in the NWU Harvard style, followed by the annexures.

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## CHAPTER 2: LITERATURE REVIEW

### OBESITY OM THE ADULT WITH INTELLECTUAL DISABILITY

#### 2.1 Introduction

The aim of this literature review is to give a comprehensive overview of obesity in AWID. This will include the impact of obesity on the health of adults with ID. Furthermore, this literature review will discuss factors that play a role in the increased prevalence of obesity in AWID, followed by a review of intervention strategies.

Obesity in the general population has been described as a global pandemic (Ng *et al.*, 2014:766; Popkin *et al.*, 2012:3). A study done in 2015, in 195 countries, found that a total of 107.7 million children and 603.7 million adults are obese (Afshin *et al.*, 2017:13). According to Popkin *et al.* (2012:3) obesity has more than doubled around the world since the eighties. Obesity and overweight in individuals with ID is also a global concern (Emerson, 2005:134; Emerson, 2011:155; Fox *et al.*, 2014:175; Melville *et al.*, 2008:425; Melville *et al.*, 2005:125). Various researchers have found that the prevalence of overweight and obesity in AWID is higher than in individuals without ID (Grondhuis and Aman, 2014:787; Maiano, 2011:189; Melville *et al.*, 2008:425; Hsieh *et al.*, 2014:851). In a cross-sectional study, it is indicated that 39.3% of women and 27.8% of men with ID are obese compared to 25.1% of women and nearly 22.7% of men in the general population (Melville *et al.*, 2008:425). In a study done on 3499 learning disabled people in the USA living in the community, the obesity rate reported is 34.6% from 1997 to 2000 (Yamaki, 2005:1). Another study in North England found obesity rates to be 27% among 1304 AWID (Emerson, 2005:134).

The high prevalence of obesity is of great concern because of the link between obesity and non-communicable diseases (NCDs) such as DM, CVD, hypertension, stroke, and certain cancers (Nguyen and Lau, 2012:326). The prevalence of NCDs associated with obesity is higher among AWID (Carmeli *et al.*, 2004:180; Rimmer *et al.*, 2010:1; Van de Louw *et al.*, 2009:78).

This combination of disability and obesity can start a series of events where obesity related health problems for AWID leads to further restriction in functioning and increases dependence on others (Froehlich-Grobe and Lollar, 2011:541). People with disabilities may be more likely to gain weight because of a sedentary lifestyle, marked by physical inactivity (Froehlich-Grobe and Lollar, 2011:541). Reasons for lower levels of activity are physical limitations due to their disability; limited opportunities; dependence on others; and motivation (Cartwright *et al.*, 2015:103; CDC, 2005:1021; Chapman *et al.*, 2008:311). Another increased risk for obesity in

the AWID is that researchers have reported a low quality dietary intake in this population (Ferraro *et al.*, 2002:834; Lakdawalla *et al.*, 2004:168). Consequently, the financial liabilities of the AWID, their caregivers, and their families increase because assistive devices (such as wheelchairs, scooters, and prosthetic devices to improve their ability to move) for obese AWID are expensive (Pain and Wiles, 2006:1212). Moreover, obese AWID need a higher level of care (Pain and Wiles, 2006:1211) and are more vulnerable to psychological problems and social discrimination due to stigmatisation (Hill, 2009:346). The substantial effect of obesity in this marginalised population can be summarised as reducing life expectancy; increasing the risk of several diseases; compromising quality of life; and increasing the financial liabilities of their caregivers (Beeken *et al.*, 2013:1; Cooper *et al.*, 2004:414).

There are a few major reasons for these health inequalities in AWID. The AWID have a poor awareness of their health needs and rely on their caretakers (family, paid caregivers) and health care professionals for support, information, and treatment (Bhaumik *et al.*, 2008:296; Cooper *et al.*, 2015:10). Thus, AWID are dependent on others to receive quality medical treatment (Krahn *et al.*, 2006:75). Furthermore, health care professionals have a lack of knowledge in the support and treatment of AWID (Bhaumik *et al.*, 2008:287; Hamilton *et al.*, 2007:339). AWID have the same rights as any other person to be treated, and those with obesity should not be ignored and left untreated (Cooper *et al.*, 2004:41; Cooper *et al.*, 2015:6; Emerson, 2011:155). Furthermore, AWID have a greater risk of poor health due to chronic medical conditions associated with disability (Emerson & Baines, 2011:43; Kinne *et al.*, 2004:443). More AWID are suffering from multi-morbidity (two or more conditions added to the ID diagnosis) compared to the non-disabled population, consequently needing specialist health services from a younger age compared to the non-disabled population (Cooper *et al.*, 2015:1). Moreover, when an individual with ID has communication difficulties or has low health literacy, he or she will not be able to communicate health problems (Cooper *et al.*, 2015:7). Finally, AWID are more vulnerable to low socio-economic circumstances (such as poverty, unemployment, social isolation, and poor housing) that may negatively affect their health (Cooper *et al.*, 2015:10; Emerson, 2011:155).

It was in reaction to these health inequities that Beange (1999:286) suggests fifteen (15) goals for better health care in AWID. These goals include recommendations to assess the nutritional status through anthropometric measures, and dietary intake measures. Another goal is to provide exercise opportunities to the AWID (Beange, 1999:291). Despite these suggestions, the prevalence of obesity in AWID are still higher than in the general population (Hsieh *et al.*, 2014:851; Melville *et al.*, 2008:425; Rimmer *et al.*, 2010:2). A more recent study underlines the importance of the development of an intervention programme, specifically developed for the

AWID (Beeken *et al.*, 2013:2; Cooper *et al.*, 2004:414). The call-out made by Beange (1999:292) in the previous millennium is still relevant for today: “Avoidable deaths and avoidable illnesses should be identified and prevented if people with disabilities are to live decent lives.”

## **2.2 Health consequences of overweight and obesity in adults with intellectual disability**

The life expectancy of AWID (and the general population), has increased due to the advances in medicine, improved health and social services, and technology to name but a few (Fisher and Kettl, 2005:26). The most significant change in life expectancy is observed in people with Down Syndrome (DS), where their life expectancy increased from 9 to 11 years in 1900, to 56 years in 2000 (Carmeli *et al.*, 2003:298; Thorpe *et al.*, 2012:1). Despite the increased life expectancy in AWID, the non-disabled population lives longer than the disabled population (Bittles *et al.*, 2002b:M470; Thorpe *et al.*, 2012:1). Compared to non-disabled adults, AWID have an increased mortality by four to six times (Bazzano *et al.*, 2009:S201; Tyrer *et al.*, 2007:520), consequently leading to an increased risk of early death (Florio & Troller, 2015:384; Heslop & Glover, 2015:414; Koritsas & Lacono, 2016:355). People with ID experience an increased burden of multi-morbidity, which starts at age 20 to 25 compared to age 50 to 54 in the typical adult (Cooper *et al.*, 2015:1). Therefore, individuals with ID suffer from premature ageing (Carmeli *et al.*, 2004:180). Undeniably, overweight and obesity have created an additional threat to the health of AWID (Maiano *et al.*, 2014:1914).

In a study by McGuire *et al.* (2007:497) done in the west of Ireland on 156 AWID, 68% of the study sample is overweight or obese. The participants with ID in the study have a mean body mass index (BMI) of  $27.7 \pm 5.69$  kg/m<sup>2</sup>, where 37.7% and 30% are overweight and obese respectively (McGuire *et al.*, 2007:497). In a study in the United Kingdom (UK), Bhaumik *et al.* (2008:287) calculated the BMI of 1119 ID adults and report 28% and 20.7% to be overweight and obese, respectively. The women with ID in the study have a higher obesity prevalence rate compared to the men with ID (Bhaumik *et al.*, 2008:287). Another UK study (on 1542 community living AWID) found similar results, where 28% are overweight and 27% are obese. The women with ID between 35 and 74 years are more likely to be obese than the men with an ID of the same age (Emerson, 2005:134). In a another large scale study (n = 945) in the UK, Melville *et al.* (2008:425) report the obesity prevalence of 39.3% in the women with ID and 27.8% in the men with ID, compared to 25.1% and 22.7% of the non-disabled population respectively. Moreover, the mean BMI of the women with ID is significantly higher than the mean BMI of the men with ID (Melville *et al.*, 2008:425). In a study done in the Netherlands, 945 AWID older than 50 years were studied. According to the BMI, the prevalence of overweight and obesity are 38.2% and 25.6% respectively. In this research study, the following individuals are significantly more likely to be overweight or obese: women with ID; individuals

with DS or autism; older AWID; less severe AWID; AWID that are able to buy and prepare their meals independently; AWID with low physical activity; and those AWID using anti-psychotic substances (de Winter *et al.*, 2012b:398).

There is an increased risk for medical conditions in AWID related to overweight and obesity for example DM, CVD, hypertension, certain cancers, osteoarthritis, respiratory problems, sleep apnea, and early death (Doody, 2012:2; Taggart & Cousins, 2014:9; WHO, 2016b).

### **2.2.1 Diabetes Mellitus (DM)**

Diabetes mellitus is classified as a chronic disease. The  $\beta$ -cells of the pancreas do not produce enough insulin or the insulin produced, does not function properly. Consequently, blood glucose concentrations increase that cause damage to various body systems (DeFonzo *et al.*, 2015:22). There are two types of DM. Type 1 (T1DM) is where the pancreas does not produce insulin due to an autoimmune reaction (the cause of this reaction is not known) or due to  $\beta$ -cell destruction (etiology and pathogenesis not known) (DeFonzo *et al.*, 2015:1007). Type 1 DM usually develops early in life (children and adolescents), yet Type 2DM (T2DM) is more common in adults (WHO, 2017b); 90% of people with DM suffer from type T2DM (WHO, 2016a). In T2DM the body does not respond properly to insulin, due to insulin resistance or inadequate insulin secretion.

According to two recent systematic literature reviews, it appears that the risk of developing and the prevalence of DM in AWID might be higher than in the general population (MacRae *et al.*, 2015:370; McVilly *et al.*, 2014:897). In one systematic literature review, the average prevalence of DM in AWID (22 studies) is 8.3 %. Additionally, in eight of the 22 studies, the prevalence rates are significantly higher than in the general population (MacRae *et al.*, 2015:356). In the other systematic literature review, the mean prevalence rates of DM in AWID are 8.7% (ranging from 3.4% to 18.5%) (McVilly *et al.*, 2014:900). The increased risk for developing DM in AWID is due to increased risk factors such as a sedentary lifestyle (with low activity levels); consumption of a diet high in fat; added sugar and salt intake; and low in fibre diets, resulting in the high prevalence rates of obesity in AWID (MacRae *et al.*, 2015:353). Furthermore, the use of psychotropic medication (Buse *et al.*, 2003:164; Newcomer, 2005:1); having a serious mental illness (Lunsky *et al.*, 2011:830); and advanced age (Haveman *et al.*, 2011:49) increase the risk of developing DM. Another possible reason is that the life expectancy of AWID has increased, making AWID more prone to develop T2DM (Bittles *et al.*, 2002a:M470). Noteworthy is that individuals with DS (Anwar *et al.*, 2004:1) and autistic spectrum disorder (Taggart *et al.*, 2013:1152) have a higher prevalence of T1DM than individuals with other diagnoses of ID (Anwar *et al.*, 2004:1).

Adults with ID need continuous assistance and encouragement of caregivers, family, and professionals for the effective management of DM (McVilly *et al.*, 2014:901; Trip *et al.*, 2016:789). Consequently, good knowledge about the management of DM is essential for caregivers and AWID, which is not currently the case (Maine *et al.*, 2017:76). Education of self-management is essential and, therefore, effective resources need to be developed and validated for AWID (McVilly *et al.*, 2014:902). Researchers suggest tailor-made educational programmes for AWID and their caregivers to optimise management of DM in AWID (MacRae *et al.*, 2015:370; McVilly *et al.*, 2014:897). McVilly *et al.* (2014:902) suggest a need for further research and encourage AWID to participate in research. MacRae *et al.* (2015:352) note that current health programmes for the general population could be adapted for AWID.

### **2.2.2 Cardiovascular disease (CVD)**

Cardiovascular disease is the biggest cause of deaths, accounting for 31% of all deaths worldwide (WHO, 2017a). Cardiovascular disease consists of a group of disorders affecting the blood vessels and the heart (coronary heart disease; cerebrovascular disease; peripheral arterial disease; rheumatic heart disease; congenital heart disease; deep vein thrombosis; and pulmonary embolism) (WHO, 2017a). Risk factors for heart attacks and strokes are: smoking, a sedentary lifestyle, excessive use of alcohol, hypertension, DM, hyperlipidaemia, obesity, and a nutritionally inadequate diet (high in sodium and saturated fat; and low in fruit, vegetables, and fibre) (WHO, 2017a). Heart attacks and strokes occur when a combination of these risk factors are present in an individual (WHO, 2017a).

Cardiovascular disease is also the number one cause of death in AWID in most western countries (Haveman *et al.*, 2010:59). Even though the prevalence rates of CVD in the ID population is lower than in the general population (Banks *et al.*, 2016:2), it is on the rise (Erickson *et al.*, 2016:371). One of the possible reasons is that AWID are living longer due to improved health care and living conditions (Draheim, 2006:3; Erickson *et al.*, 2016:371). However, the prevalence of CVD in older AWID matches that of the general population (de Winter *et al.*, 2016:53).

De Winter *et al.* (2012a:1723) investigated the prevalence of conditions associated with CVD (such as DM, hypertension, hypercholesterolemia, and metabolic syndrome) in 980 older adults with mild to profound ID, in a Dutch community. Other risk factors such as gender, age, smoking, living arrangements, physical activity, and obesity are also investigated. The prevalence of DM, hypertension, and hypercholesterolemia is similar to the general population. Moreover, they have found that risk factors for CVD are not diagnosed in 45%-50% of the participants. Indeed, 50% of those with hypertension were unaware of having the condition (de

Winter *et al.*, 2012a:1722). The researchers have found that women with ID, older AWID, obese AWID, and those living on their own have an increased risk for developing CVD risk factors (de Winter *et al.*, 2012a:1722).

The impact of these risk factors is lowered with increased physical activity, improved nutrition, and well-managed psychotropic medication use (Banks *et al.*, 2016:26). Caregivers should be educated to ensure that AWID are screened regularly and treated by a well-informed health care specialist (Banks *et al.*, 2016:14; de Winter *et al.*, 2012a:1729). In fact, knowledgeable and active involved caregivers and medical staff are necessary for the management of CVD (Banks *et al.*, 2016:14).

### **2.2.3 Cancer**

About 12.7 million people are diagnosed with cancer and 7.6 million die from cancer each year; making it one of the leading causes of death in the world (Ferlay *et al.*, 2010:2893). A recent umbrella review of 95 meta-analyses found that there is a positive association between the risk of developing certain cancers and body fat (Kyrgiou *et al.*, 2017:1). Strong evidence indicates that overweight people have an increased risk to develop 11 different cancers: pancreatic, kidney, ovarian, biliary tract, oesophagus, colon, rectum, bone marrow, stomach, breast, and endometrial cancer. Due to the high prevalence of obesity in AWID (de Winter *et al.*, 2012b:398; Yamaki, 2005:1), this may greatly effect cancer risk in this vulnerable population.

Cancer incidence in AWID are not well documented (Forbat and McCann, 2010:91). The incidence of cancer in the ID population before the move from institutions tends to be lower in AWID than in the general population (Forbat and McCann, 2010:91; Hogg & Tuffrey-Wijne, 2008:509). A study in Australia on a database from 1982 to 2001 (after their move) reports that the incidence rates of all cancer in the ID population are the same compared to the general population (Sullivan *et al.*, 2004:1022). Despite these reports, researchers warn that cancer incidence are likely to increase among AWID because of their increase in life expectancy (Hogg & Tuffrey-Wijne, 2008:509; Janicki *et al.*, 1999:6; Maaskant *et al.*, 2002:201; Sullivan *et al.*, 2004:1021). A research study advises health care professionals to increase their health screenings in the ID populations. This will lead to earlier detections of cancer and, consequently, increase survival rates of AWID (Sullivan *et al.*, 2004:1021). Certain cancers affect AWID more than others (Sullivan *et al.*, 2004:1021; Yang *et al.*, 2002:1019). Women with ID have an increased risk for leukaemia, corpus uteri, and colorectal cancers, where ID men have an increased risk for leukaemia, brain, and stomach cancers. It is important to note that ID men have a lower risk for prostate cancer compared to non-disabled men (Sullivan *et al.*,

2004:1024). Similar results in a study by Yang *et al.* (2002:1019) indicate that the incidence of prostate and testicular cancer is lower in ID men compared to non-disabled men.

The predicted rise in cancer incidence in AWID is confirmed in a recent study in the UK, where the cause-specific mortality rates were studied in 16 666 ID adults and were compared to the cause-specific mortality rates in 113 562 non-disabled adults from 2009 to 2013. The cause-specific death rates due to neoplasm is 19.8 and 14.9 per 10 000 people per year for the AWID and the general population respectively (Hosking *et al.*, 2016:1486).

#### **2.2.4 Respiratory problems and sleep apnoea**

People with ID have higher prevalence rates of respiratory diseases (especially asthma) than the non-disabled population, and are one of the more prevalent causes of death in the ID population (Axmon *et al.*, 2017:1). In addition, AWID have higher rates of hospital admissions, emergency room visits, and prolonged hospitalisation due to respiratory diseases compared to the non-disabled population. Moreover, when an individual suffers from obesity, their risk for developing asthma is increased (Kim *et al.*, 2014:189). Research in humans and mice indicates correlations between obesity and asthma regarding prevalence and severity. More focused research is needed to clarify the mechanisms (Kim *et al.*, 2014:192). Indeed the prevalence rates of asthma in obese individuals are higher compared to individuals with a normal weight (Kim *et al.*, 2014:189). Consequently, obesity in adults with ID increases their already increased risk for developing respiratory diseases. Therefore, regular medical check-ups are essential in preventing and treating respiratory illnesses in AWID (Axmon *et al.*, 2017:2).

Approximately 35% to 90% of AWID experience sleep disturbances such as sleep apnoea, restless leg syndrome, and insomnia (May & Kennedy, 2010:7). There seems to be a link between obstructive sleep apnoea (OSA) and obesity (Romero-Corral *et al.*, 2010:711). OSA affects different organs and organ systems in the body that play a role in cardiovascular disease. Furthermore, OSA is associated with hypertension, insulin resistance, systemic inflammation, dyslipidaemia, and obesity. Weight loss is considered to be an important treatment of obesity and OSA (Romero-Corral *et al.*, 2010:711).

### **2.3 Factors associated with overweight and obesity in adults with intellectual disability**

The higher prevalence of obesity in AWID is due to a complex mix of behavioural, environmental and biological factors. Some of these associated factors are described as “non-modifiable precursors” (constant and unchanging factors) and others as “modifiable risk factors” (changeable factors) (Rimmer *et al.*, 2011:1729). Unchangeable risk factors are age, severity of ID, being female, and certain genetic syndromes such as DS (Bhaumik *et al.*, 2008:288; de

Winter *et al.*, 2012b:400; Rimmer *et al.*, 2011:1730). Changeable risk factors can be divided into personal and environmental factors (Hsieh *et al.*, 2014:852). Although substantial research has been done on changeable risk factors in the non-disabled population, not enough research has been done in AWID (Hsieh *et al.* 2014:852). The following personal changeable factors are identified through research: use of anti-psychotic, anti-depressant, anti-hypertensive, or some diabetes-related medications (Bokszanska *et al.*, 2003:285; Cohen *et al.*, 2001:114); sedentary lifestyle and/or physical inactivity (Cartwright *et al.*, 2015:103; Dairo *et al.*, 2016:209; Draheim *et al.*, 2002:361; Mikulovic *et al.*, 2014:153); and poor dietary intake (Adolfsson *et al.*, 2008:1; Hamilton *et al.*, 2007:339; Ptomey. *et al.*, 2013:625). For optimum planning and implementation of intervention programs in AWID, a comprehensive understanding of the role of these risks factors is essential (Melville *et al.*, 2007:223). These risk factors do not work in isolation, and therefore, large study populations are needed to make use of multivariate statistical methods to explore possible associations between the risk factors and other variables (such as anthropometric measurements) (Melville *et al.*, 2007:228).

### **2.3.1 Unchangeable risk factor: gender**

Various research studies indicate that women with ID have higher rates of obesity compared to men with ID. In three USA studies, the prevalence of obesity in women with ID is 43.2%, 58.5% and 44.25% respectively (Hsieh *et al.*, 2014:855; Rimmer *et al.*, 1993:105; Yamaki, 2005:1). In fact, the prevalence of morbid obesity in the women with ID, in a USA study, is two times the prevalence than in the men with ID (10.9% *versus* 4.9%) (Hsieh *et al.*, 2014:851). Bhaumik *et al.* (2008) report obesity prevalence in women with ID (29%) to be almost double that of the men with ID (15%) ( $p < 0.001$ ) and Robertson *et al.* (2000:475) report a statistical significant ( $p < 0.05$ ) higher proportion of women with ID to be obese (24%) compared to the general population (18%). The prevalence of obesity in women with ID is higher than in women without an ID (Bhaumik *et al.*, 2008:291; Melville *et al.*, 2007:223). A study in the Netherlands shows obesity prevalence in women with ID to be 37.2% compared to 17.5% in the women without an ID, which is more than twice the prevalence in the population without an ID (de Winter *et al.*, 2012b).

Similarly, the prevalence of obesity in the ID men has been measured by the three USA studies and is reported as 34.3%, 27.5%, and 26.5% respectively (Hsieh *et al.*, 2014; Rimmer *et al.*, 1993:105; Yamaki, 2005:2). Rimmer *et al.* (1993:105) and Yamaki *et al.* (2005:1) report higher obesity prevalence in the men with an ID (27.5% and 26.5%) compared to the men without an ID (19% and 20.3%). In the UK, prevalence of obesity in the men with an ID ranges from 2% to 15%, which is lower than the USA studies (Bhaumik *et al.*, 2008:287; Cunningham *et al.*, 1990:3; Robertson *et al.*, 2000:469). In contrast to the previous discussion on obesity,

overweight rates in men with an ID are higher compared to women with an ID in some studies (Bhaumik *et al.*, 2008:287; de Winter *et al.*, 2012b:398; Hsieh *et al.*, 2014:851; Robertson *et al.*, 2000:469).

### **2.3.2 Unchangeable risk factor: age**

Melville *et al.* (2008:425) did find a unique association between age and weight status in AWID that are different from non-disabled adults. In the non-disabled population, weight increases steadily to reach a peak at 60-70 years, followed by a decrease in weight (Melville *et al.*, 2008:426). In contrast, AWID have a sudden rise in weight early in their adult life where it peaks and is then maintained, until it lowers in the later stages of life (Melville *et al.*, 2008:433). Consequently, AWID reach their peak weight approximately 20 years before the non-disabled population (Melville *et al.*, 2008:433). This increased obesity prevalence of AWID at a younger age increases their risk for developing NCDs such as CVDs, DM, and certain cancers earlier in life (Emerson, 2005:134; Melville *et al.*, 2008:425; Yamaki, 2005:7). The possible reasons for this earlier development of obesity in ID adolescents are a sedentary lifestyle, dependence on others, and boredom. More research is needed in ID adolescents to explore this association (Melville *et al.*, 2007:227).

Emerson (2005:140) found a positive association between older age and physical inactivity in AWID ( $p < 0.05$ ). This is of great concern because physical inactivity is associated with increased risk of CVD, T2DM, and some cancers (Emerson, 2005:141). Another research team in the UK, who studied BMI in 1119 AWID above 20 years, found a negative association between age and underweight (Bhaumik *et al.*, 2008:292). They have found that with increased age (in men and women), the prevalence of underweight decreases. Consequently, 32%, and 25% respectively of the men and women with an ID are underweight at age 20 to 29 years. Additionally, those aged 50 and over 15% and 9% respectively of the men and women with an ID, are underweight (Bhaumik *et al.*, 2008:292).

### **2.3.3 Unchangeable risk factor: diagnosis**

A USA study (Hsieh *et al.*, 2014:856) reports that adults with DS have the highest prevalence of obesity (53.4%) and morbid obesity (10.4%) compared to AWID with unknown aetiology, autism, and cerebral palsy. By comparison, a negative correlation is reported between obesity and cerebral palsy (Hsieh *et al.*, 2014:858). Similar results were found by Bhaumik *et al.* (2008:287) in the UK, where those with DS have an increased risk of obesity (OR 2.30; 95% CL 1.76-4.06) and again those diagnosed with cerebral palsy are less likely to be obese (OR 0.07; 95% CL 0.01-0.59). It may seem that people with DS are more likely to be obese than other ID

adults. A study by Melville *et al.* (2005) has found that the DS women have a higher prevalence of obesity than other AWID. The cause of the higher prevalence of obesity in DS is unknown (Bhaumik *et al.*, 2008:295). A low quality, high energy dietary intake, a lack in dietary knowledge and risks of obesity, low levels of exercise, a sedentary lifestyle, and low income are all factors that may influence the development of obesity in the DS individual (Bhaumik *et al.*, 2008:287; Melville *et al.*, 2005:125; Prasher, 1995:437). Additionally, some other genetic syndromes such as Prader-Willi, Cohen, Borjeson, Carpenter, and Bardet-Biedl syndromes in AWID are predisposed to obesity (Allison *et al.*, 1998:215; Melville *et al.*, 2007:223).

### **2.3.4 Changeable risk factor: residential type**

In a review by Ranjan *et al.* (2017:7) it is described that AWID living in a more controlled environment, where there is more staff support, have a lower BMI than those living independently (having more freedom of choice) and those living with limited staff support. In a large UK study (1119 AWID) by Bhaumik *et al.* (2008:295) it is found that the BMI of those living with family and independently is significantly higher than those living in a more controlled environment. AWID with more freedom of choice; being able to eat, drink and buy their own food without help, are more likely to be overweight and obese (Bhaumik *et al.*, 2008:295; de Winter *et al.*, 2012b:398). These results are consistent with previous studies where a more controlled residential environment lends itself to support and guidance regarding food intake and monitoring of weight (Prasher, 1995:437; Rimmer *et al.*, 1995:489; Robertson *et al.*, 2000:469).

Hsieh *et al.* (2014) further report that ID adults living in non-rural settings with no-one watching over them, have significantly higher consumption rates of fast foods, salty snacks, sugar sweetened beverages (SSBs), and significantly lower consumption of fruits and vegetables. Additionally, the AWID watch more TV; smoke and drink alcohol more frequently, and have poor oral hygiene compared to those living in more controlled settings with caregivers (Hsieh *et al.*, 2014:851; Mikulovic *et al.*, 2014:153). Bhaumik *et al.* (2008) report the difficulty experienced by researchers to identify and interpret changeable risk factor links with socio-economic status. In their clinical experience, they observed that some family caregivers have insufficient healthy eating and obesity risk knowledge because of their own isolation. Moreover, they have limited education and practical support to improve the life of the ID adult in their care. Some of them will overprotect the ID individual by not participating in community activities, and consequently, compensate by overfeeding the ID person. Challenging behaviour in some ID adults makes it difficult for the family caregivers to resist the individuals' demands for food (Bhaumik *et al.*, 2008:287).

The level of disability plays a role in the obesity risk where adults with a severe ID had significantly lower levels of obesity compared to ID adults with moderate, mild, or borderline ID (Hsieh *et al.*, 2014:851). Melville *et al.* (2007:223) report that individuals with a mild to moderate ID have a higher prevalence rate of obesity than individuals with a severe ID. Those with a mild ID are more likely to live in an unsupported environment with a lack in ID services and health checks. Moreover, those with mild disabilities live more independently, and face more barriers with regards to accessing health and social services, consequently having a negative effect on their socio-economic status, health, and general well-being (Melville *et al.*, 2008:425). These observations underline the importance of support by paid caregivers and the family of AWID (Hamilton *et al.*, 2007:339).

### **2.3.5 Changeable environmental risk factor: health support**

People with ID experience several challenges in accessing health care services (Hamilton *et al.*, 2007:344). One of these challenges is a lack of transport, and dependency on caregivers and family to provide transport to health services. A major challenge is that AWID are considered as a minority group and are not seen as a priority by governments. This underlines the importance of a change in political and organisational attitudes towards the health needs of AWID (Krahn *et al.*, 2006:78). Additionally, there is paucity in knowledge among healthcare professionals in the support and treatment of ID adults because of a lack in training (Krahn *et al.*, 2006:74). Due to communication difficulties, AWID are not able to express themselves regarding symptoms and health needs. Moreover, ID adults are dependent on the assistance of family and caregivers in identifying health problems; assessing health services; and being their health advocates (Bhaumik *et al.*, 2008:297; Hamilton *et al.*, 2007:344).

Health care professionals and general practitioners (GPs) have a responsibility in the diagnosis and prevention of weight issues in AWID, but it is not always the case. In a study by Hsieh *et al.* (2014:860) it was reported that only one third of overweight or obese AWID are advised to lose weight by health care professionals. The dietician or nutritionist has to provide tailor-made nutrition information, and training to paid caregivers, family members, and adults with ID in menu planning, finances, food safety, nutrition, and an understanding of health risks of obesity (Walter *et al.*, 1997). In a more recent review, the important role of the GP is highlighted; being the healthcare professional serving the AWID from a young age into adulthood (Hemm *et al.*, 2015:109). There is a need for further qualitative research regarding the attitudes and knowledge of healthcare professionals towards AWID (Hsieh *et al.*, 2014:860). Equally important is a need in research that evaluates the training needs for healthcare professionals regarding the ID population (Hemm *et al.*, 2015:109).

### 2.3.6 Changeable personal risk factor: medicine

In a recent review, it was described that prescription medications (antidepressants, anticonvulsants, DM medications, and anti-hypertensives) are consistently associated with weight gain of up to 15 kg in several months (Ranjan *et al.*, 2017:7). The two mechanisms linked to weight gain is a reduction in the metabolic rate, and an increase in appetite (corticosteroids) (Pijl & Meinders, 1996:329). Anti-depressants (for example, Paxil and Zoloft); anticonvulsants (for example, Depakote); DM medication (for example, Diabeta and Diabinese) and anti-hypertensives (for example, Cardura and Inderal) may increase body weight (Heal *et al.*, 2012:136). The use of psychotropic medication in adults with ID not only plays a major role in weight gain, but also causes negative cardiac changes (Newcomer, 2005:11-16). This ID population are already at risk of developing obesity at an earlier age, leading to health problems related to obesity (Doody, 2012:460), adding the increased weight gain due to use of medication, increases the risk for the development of NCDs. This observation highlights the importance of regular health monitoring in this population (Newcomer, 2005:84).

Health professionals should prescribe alternative medication to ID adults that do not have an effect on body weight (Hsieh *et al.*, 2014:859). Behavioural strategies (for example, diet or exercise) can be followed so that medication use can be reduced or replaced completely. In fact, it is critical that ID adults with morbid obesity follow behavioural strategies to reduce their increased risk for CVD, cancer, DM, and mortality (Lenz *et al.*, 2009:641).

### 2.3.7 Changeable personal risk factor: physical activity

Physical inactivity and poor diet is associated with NCDs (for example, CVD, cancer, DM, osteoporosis) (Booth *et al.*, 2012:1143; Popkin *et al.*, 2006:271). Individuals with CVD and/or DM usually suffer from obesity, dyslipidaemia, or hypertension (Anon, 2015:470). When the latter is combined with other poor lifestyle habits such as smoking, excessive intake of alcohol, poor diet (high fat and salt intake) and lack of physical activity, the risk for developing NCDs increases (Nojilana *et al.*, 2016:477). Yet, increased habitual physical activity can reduce the risk of NCDs and consequently, improve quality of life (Botha *et al.*, 2013:S20; Booth *et al.*, 2012:1143). Nevertheless, various studies in people with ID have revealed a low level of physical activity (Barnes *et al.*, 2013:1048; Bhaumik *et al.*, 2008:287; Dowling *et al.*, 2012:1; Hsieh *et al.*, 2014:851; Koritsas & Lacono, 2016:355).

The recommended physical activity guideline for Americans is 150 minutes of moderate intensity exercise, and a further 75 minutes of vigorous intensity aerobic exercise per week (WHO, 2011). The FBDGs of SA recommend moderate intensity exercise for 40 to 60 minutes

on most days of the week. In addition, physical activity can be accumulated throughout the day in 10 minute exercise sessions (Botha *et al.*, 2013:S24). Similarly, the WHO guidelines suggest that adults should do 150 minutes of moderate intensity, aerobic exercise per week. For weight loss purposes, individuals should engage in exercise for 300 minutes per week of which 75 minutes should be vigorous (WHO, 2011). It is recommend that AWID (if they are able to), should try to meet the physical guideline for non-disabled adults (Hsieh *et al.*, 2014:859).

In a review of 14 research studies on physical activity in AWID, Dowling *et al.* (2012:1) report that there are significant positive health outcomes regarding physical activity in AWID. They found that AWID not only experience positive health outcomes with exercise, but also positive social and emotional outcomes. The latter influences their quality of life in a positive way (Dowling *et al.*, 2012:5). This is supported by an intervention study done on DS adults with ID in care centres in SA, where the researchers found that exercise (interval and continuous aerobic training) can improve the anthropometry, fitness level, and functionality of AWID (Boer & Moss, 2016:1). Interval training, however, has a greater impact on body weight than continuous aerobic training (Boer & Moss, 2016:1). Similarly, AWID participating in biking, running, basketball, and outside chores have significantly lower BMI than those who do not participate (Barnes *et al.*, 2013:1048).

However, people with ID experience various obstacles to participating in physical activity (Frey *et al.*, 2005:241; Messent *et al.*, 1999:409; Nhamo & Sibanda, 2014:304). A few obstacles are an overprotective and negative outlook of caregivers (no support); a fear that exercise may cause injuries; no transport available; lack in finances; time constraints because of employment; and low accessibility to physical activities (Frey *et al.*, 2005; Messent *et al.*, 1999).

### **2.3.8 Changeable personal risk factor: dietary intake**

Malnutrition has typically been associated with a state of under-nutrition, but it has been established that malnutrition can also be associated with obesity (or over-nutrition) (Tanumihardjo *et al.*, 2007:1966). Diets of AWID have adequate energy, but lack the quality needed for optimal health and prevention of chronic disease (Tanumihardjo *et al.*, 2007:1966). Traditionally, AWID are known for under-nutrition, but nowadays this vulnerable population displays the same pattern as the general population, that is, being over-nourished (Tanumihardjo *et al.*, 2007:1966). Accurate determining of dietary intake in AWID is a challenge and may explain the paucity in dietary research done in AWID (Hoey, 2015:44). Nutritionists and dietitians use different measurements to determine the nutritional status and risks within an individual or population. Measurements need to be validated before the results obtained can be justified for the specific population (Humphries *et al.*, 2009:164). There is no validated

measurement of dietary intake in AWID because some have problems with memory, comprehension and communication that lead to difficulties in determining and recording quantities of food intake (Humphries *et al.*, 2008:169; Humphries *et al.*, 2009:165). A suitable method in collecting dietary intake, in a controlled environment such as institutions and long-stay hospitals, is to make use of a 24-hour proxy reporter (Humphries *et al.*, 2009:166). However, collecting dietary data from ID adults living in the community settings is more challenging. A proxy reporter only records food that the reporter sees the participant consume, consequently, unsupervised dietary intake is not recorded (Humphries *et al.*, 2009:166). As more AWID become independent, a combination of measurement methods is recommended, for example, a combination of the use of a proxy, interviews and self-reporting. Moreover, this method still needs to be validated in the ID population (Humphries *et al.*, 2009:166).

Despite this lack in a validated measuring method in dietary intake, researchers around the world have done various dietary intake studies (Humphries *et al.*, 2009:164). Dietary intake studies before the move of AWID from institutionalised settings to community settings were mainly in controlled settings such as long-stay hospitals and institutions (Humphries *et al.*, 2009:164). Bryan *et al.* (2000) evaluated the overall nutritional status before and after the move from a large long-stay hospital setting to small residential settings. They used a diet screening form to evaluate diet adequacy, weight, and dietary problems a month before the move, and again one year after the move. At the second screening, more AWID were underweight and overweight than at the first screening. There is a statistically significant increase in being at nutritional risk among the men in the study. These results are a concern and therefore, further support and monitoring by dietitians are recommended (Bryan *et al.*, 2000:267).

Various researchers were concerned about the dietary intake of AWID in their new living conditions (in community settings) and therefore, extensive research was done in the UK (Bhaumik *et al.*, 2008:287), USA (Braunschweig *et al.*, 2004:186; Draheim *et al.*, 2007:392; Hsieh *et al.*, 2014:851; Ptomey. *et al.*, 2013:625), Italy (Bertoli *et al.*, 2006:100), Ireland (McGuire *et al.*, 2007:497; Hoey, 2015:1) and Sweden (Adolfsson *et al.*, 2008:1) to assess the dietary intake in AWID. The nutritional intake of AWID in community settings were characterised by a lower consumption of complex CHO and high intakes of refined CHOs (such as sugar) (Hoey, 2015:68); total and saturated fat (Hoey, 2015:68); and sodium (Bertoli *et al.*, 2006:110; Braunschweig *et al.*, 2004:186). An inadequate dietary intake of fibre (Braunschweig *et al.*, 2004:186; Hoey, 2015:68) leading to constipation, is observed (Bertoli *et al.*, 2006:110). The overall consumption of fruits and vegetables are low (Adolfsson *et al.*, 2008:1; Braunschweig *et al.*, 2004:186; Draheim *et al.*, 2007:392; McGuire *et al.*, 2007:497; Ptomey. *et al.*, 2013:625). Some researchers report a low intake of dairy (calcium) (McGuire *et al.*,

2007:501). Moreover, AWID have a high consumption of SSBs and fruit syrups (Adolfsson *et al.*, 2008:1; Hsieh *et al.*, 2014:860). In fact, 60% of the ID participants drank a tin of carbonated cool drink once or twice a day. There is an association between SSBs consumption and increased obesity prevalence (Te Morenga *et al.*, 2012:1). It is critical to promote better nutritional habits in the ID population to reduce obesity rates. One critical habit to change is to replace SSBs consumption with water consumption (Hsieh *et al.*, 2014:861).

In a large UK study (in community settings) that assessed the risk factors for obesity development, 4% of the participants have food intake issues such as pica, continual eating/drinking, and self-induced vomiting (Bhaumik *et al.*, 2008:287). These habits are part of a range of eating disorders (ED) found in AWID. Research studies have found that people with ED and with ID prevalence in institutions is 3%-42% and in community settings 1%-19% (Gravestock, 2000:625). In this early review by Gravestock (2000) on people with ED and ID, it is found that ED is more common in those living in controlled long-stay hospital settings, younger adults, males, severe ID, overweight or underweight, autism, and behaviour problems (Gravestock, 2000:631).

In the USA, Draheim *et al.* (2007:392) evaluated the dietary status of 325 adults (19 to 65 years) with mild to moderate ID, living in three different community residential settings. The group homes are described as a residential facility that provides supervision for 24-hours (with caregivers overnight). The second residential setting is where the AWID lives with a family member without an ID. Semi-independent residential settings provide less than 24-hour supervision with no overnight, paid caregivers. The researchers evaluated the fruit, vegetable, and fat intake *via* two validated questionnaires (Draheim *et al.*, 2007:393). The main finding is that the AWID in this study population consume too much fat and not enough fruit and vegetables regardless of their residential setting (Draheim *et al.*, 2007:392).

Only a few early studies reported dietary intake in a controlled environment (Cunningham *et al.*, 1990:3; Litchford and Wakefield, 1985:690; Molteno *et al.*, 2000:35). Financial constraints and managerial differences may have had an effect on the quality of AWID's diets. Adults with ID in a controlled environment are dependent on the staff of the institution for their dietary intake (Cunningham *et al.*, 1990:3). Molteno *et al.* (2000:1135) report on the nutritional status of AWID in a long-stay hospital setting in Cape Town, SA. The AWID receive their food from a central kitchen, prepared from a fixed menu. The BMI of the men is significantly lower than that of the women. Those with a severe mental disorder have a lower BMI than those with a mild mental disorder. The researchers report that 58%, 23% and 43% of the AWID to be underweight, overweight, and obese respectively (Molteno *et al.*, 2000:1137). The researchers recorded the dietary intake of 15 active and 15 inactive patients for seven days by means of food wastage

studies. The researchers did not explain what they meant with active and inactive, but because it is a hospital setting, it is assumed that the active patients are those able to move around easily, and the inactive patients are those in wheelchairs and have difficulty moving due to a physical disability. The macronutrient intake of both groups is within the normal range as recommended. The mean BMI of the active (21.4 kg/m<sup>2</sup>) and inactive (22.12 kg/m<sup>2</sup>) patients are similar (Molteno *et al.*, 2000:1137). Even though the dietary intake of protein is within recommendations, the quality of the protein intake is low because the main sources of protein are bread and cereals. The AWID in the active ward, receive extra snacks, and for that reason, their mean energy intake per day is higher than those in the inactive ward (10 576 kJ *versus* 8646 kJ). The AWID in the active ward complain about the small portions. The researchers report that sometimes food are stolen after leaving the kitchen and therefore, never reaches the wards, especially at suppertime (Molteno *et al.*, 2000:1139). Additionally, copper, pantothenic acid, biotin, and vitamin D dietary intake is inadequate. The researchers recommend larger portions, increased consumption of high quality protein food, and the inclusion of organ meat in the menu (Molteno *et al.*, 2000:1139). The latter is to improve the copper, biotin, and pantothenic acid intake. Another recommendation is to supplement the diet of the underweight patients with nutritional supplements, powder milk, hot chocolate, dried fruit, and fruit juices (Molteno *et al.*, 2000:1140)

Another study on dietary intake in a controlled environment was done by Cunningham *et al.* (1990:3). They assessed the dietary intake of 115 men and 217 females between 15 and 64 years in five long-stay hospital settings in Dublin, Ireland. More men (19%) are underweight than women (5%); and more women (27%) are obese than men (15%). The researchers trained the nursing staff to do a semi-weighted plate wastage study for four consecutive days. The staff recorded all food in household measures and the research team translated it to weights. Dietary intake was compared to the RDAs (Cunningham *et al.*, 1990:8). The total energy distribution for protein, CHO and fat are 18%, 39% and 43% respectively. Approximately 25 % of the women in the study have inadequate intake of vitamin B<sub>6</sub>, vitamin C, energy, and iron. The energy intake ranges from 10700 kJ to 17300 kJ per day and is determined by the meal plan followed at the specific long-stay hospital setting. The dietary intake of the AWID in this controlled setting compares well with previous studies done in community settings during the same time period (Cunningham *et al.*, 1990:9). The dietary fat intake of 43% is of concern, because of the increased risk it poses for the development of CVDs. The reason for the high fat intake was explained by the high intake of milk and meat by the participants in the study (Cunningham *et al.*, 1990:10).

In 1985, Litchford and Wakefield, in the USA, published a study on the three-day plate waste dietary intake of 80 AWID in an institution. All the AWID need assistance with dietary intake. The researchers evaluated the dietary intake of the AWID before and after the nutritional training of 70 caregivers. The dietary energy, niacin, and iron intake of the participants improved statistically significantly after the nutritional training of the caregivers (Litchford & Wakefield, 1985:690)

Malnutrition (over- and under-nutrition) is prevalent in AWID and is a result of low quality dietary intake. Moreover, the accurate recording of dietary intake in AWID is a challenge to nutrition researchers and results in a paucity of accurate dietary intake and intervention studies in the ID population (Tanumihardjo *et al.*, 2007:1966; Bertoli *et al.*, 2006).

### **2.4 Intervention studies in the adult with intellectual disability**

Increasing prevalence of overweight causing further health inequities in AWID is problematic. Without effective weight management strategies, tailor-made for this population, the combination of obesity and NCDs will be detrimental to the overall quality of life of AWID (Humphries *et al.*, 2009:176). Researchers have targeted various areas in weight management interventions such as dietary intake, physical activity, and behaviour (Willems *et al.*, 2017:256). There are various intervention methods that are found in existing literature to manage health and weight outcomes in AWID.

#### **2.4.1 Behavioural interventions**

In a review it was noted that behavioural interventions are more effective in the non-disabled population than in AWID, and there is no explanation for this finding (Hamilton *et al.*, 2007:342). The goal of behavioural interventions is to provide the individuals with techniques of self-control to make improvements in diet and exercise behaviours (Hamilton *et al.*, 2007:342; Willems *et al.*, 2017:256). Willems *et al.* (2017:256) did a systematic literature review on 45 studies that used behavioural change techniques (BCTs) in diet and exercise in AWID. The majority of the research studies did not make use of randomised controlled trials (RCTs) and the BCTs were not developed from a theoretical basis. There is a need for further research in effective behavioural interventions where the BCTs are grounded in theory; the interventions are planned comprehensively; and the studies are controlled with enough power (Willems *et al.*, 2017:256).

#### **2.4.2 Multi-component interventions (MCIs)**

Various reviews on MCIs (multi-component interventions) in AWID are published (Doherty *et al.*, 2017:1; Hamilton *et al.*, 2007:339; Jinks *et al.*, 2011:460; Spanos *et al.*, 2013b:1; Willems *et al.*,

2017:256). In two reviews by Hamilton *et al.* (2007:343) and Jinks *et al.* (2011:470) respectively it is noted that intervention studies are too small and lack control, and consequently, the efficacy of the interventions are not evaluated. Jinks *et al.* (2011:470) conclude that there are not enough qualitative studies that describe the experience of the caregivers and ID participants in the intervention studies. Even though some of the intervention studies are successful, they need to be sustainable (Jinks *et al.*, 2011:469). Consequently, it is suggested that when more than one component of intervention is used, the weight management interventions will be more successful and sustainable. For interventions to be sustainable, the AWID need to be equipped with the necessary knowledge and support to maintain their healthier lifestyle. The latter type of interventions is called multi-component interventions (MCIs) (Doherty *et al.*, 2017:2; Hamilton *et al.*, 2007:344).

The first MCI study is by Melville *et al.* (2011:1553) using the Glasgow & Clyde Weight Management Service (GCWMS), which is an ongoing service of the National Health Service (NHS) of the UK since 2004. The GCWMS was adapted for AWID and consequently a 16-week, TAKE 5 weight management programme for AWID was developed. The TAKE 5 study in Scotland (UK) combines an energy deficit diet of 2510 kJ/day, increased physical activity, and behaviour interventions. The latter consist of nine compulsory sessions during which the participants are informed on the benefits of losing weight, healthy eating, physical activity, and related topics. The diet planning and goalsetting are done on an individual basis. Family and paid caregivers are involved in the intervention, to give support and guidance to the ID participants. The intervention resulted in a significant lowering of weight, BMI, waist circumference, and sedentary behaviour of the study population (Melville *et al.*, 2011:1553).

Spanos *et al.* (2014:22) compared the ID participants in the TAKE 5 study with the non-disabled population following the GCWMS program. The GCWMS is executed in group sessions where the TAKE 5 uses individual intervention strategies, involving the carers (paid caregivers and family) of the AWID. In the TAKE 5 study, the dietitian visits the AWID in his/her residential setting for a one-on-one consultation, due to the wide range of mental and communication disabilities in AWID (Melville *et al.*, 2011:1554). Spanos *et al.* (2014:22) paired the ID participants in the TAKE 5 study with the non-disabled participants in the GCWMS that had similar characteristics. The goal was to evaluate the effectiveness of the TAKE 5 intervention. There is no reported difference between the outcomes for the disabled and non-disabled participants. The researchers conclude that MCI can be equally successful in disabled and non-disabled populations (Spanos *et al.*, 2014:22).

Bergstrom *et al.* (2013:3847) did a cluster RCT in 130 AWID living in 30 community residences. The study consists of a three component 'Social Cognitive Theory'. Two of the components

involve the caregivers. One caregiver in a residence is chosen as an ambassador to attend network meetings. His or her tasks are to provide information to other caregivers and to organise all participant activities regarding the study. The second component is an informative group meeting for all the caregivers of each residence. The group session consists of 10 meetings during which their healthy cooking skills and nutrition knowledge are improved. The third component is health education for the AWID. Diet quality is measured through photos taken by participants of their meals, but not all participants took photos of their meals. Food intake is coded and evaluated according to dietary diversity, fruit and vegetable intake, and the plate model. The plate model provides a visual guide of proportions of the plate that should be covered by certain food groups (Camelon *et al.*, 1998:1155). A pedometer is used to measure physical activity. The participants of this study have an increase in physical activity with an increase of  $\pm 1608$  steps per day. There are no significant changes in BMI, waist circumference, and diet quality (Bergstrom *et al.*, 2013:3847). A qualitative study by Sundblom *et al.* (2015:296) evaluated the implementation strategies followed in this study to improve the success of future interventions.

Sundblom *et al.* (2015:296) conducted a qualitative study for input from the residence managers and caregivers in their experiences of the execution methods used by the MCI in the Bergstrom *et al.* (2013:3847) study. Thirty to 70 minute, semi-structured interviews were conducted with 17 staff members. The first observation is that the values and goals of the MCI should be in line with the values and goals of the residents. Next, the thin line between autonomy and providing support and guidance to make the most suitable choice is discussed. The caregivers should be available to provide positive guidance to the AWID on choices in a respectful manner. Thirdly, the health education course the AWID attended was conducted in a group setting without the presence of the caregivers. Two good things came from it. It provided autonomy and the experience of learning from others in a group context. Another topic raised is the need for a flexible programme that can be adapted according to the intellectual level of the AWID in the study. Furthermore, an environment with an involved manager, good working relationships, low staff turnover, positive attitudes, and enough staff is critical to the successful implementation of the programme. Finally, staff members should have access to external support (especially when there is a high workload and not enough time) by health care providers like nurses, dietitians, biokineticists (exercise specialists), social workers, and physiotherapists (Hooren *et al.*, 2002:560; Sundblom *et al.*, 2015:304).

It is clear that MCIs can be successful when it involves the manager, caregivers, and AWID in the implementation of the programme. The programme should be well planned, allowing

individual changes according to the AWID's ability (Melville *et al.*, 2011:1553; Spanos *et al.*, 2014:23; Sundblom *et al.*, 2015:305).

### **2.4.3 The role of the caregiver in intervention**

Various research studies have recognised the role paid caregivers and/or family members play in interventions to support the AWID in their quest in changing unhealthy habits (Bergstrom *et al.*, 2013:3849; Bhaumik *et al.*, 2008:296; Hamilton *et al.*, 2007:343; Krahn *et al.*, 2006:70; Ptomey *et al.*, 2017:1). Caregivers do not only meet the needs of AWID (Ptomey *et al.*, 2017:2), but the majority AWID are reliant on them to make healthy food and lifestyle choices (Bhaumik *et al.*, 2008:288). Caregivers need support from the research team to change their own behaviour and improve their knowledge so that they (caregivers) will be able to support behaviour change in AWID (Mitchell *et al.*, 2013:4).

Caregivers experience various difficulties in the successful execution of their supportive role, such as a high turnover of caregiver staff, a lack of communication between caregiver staff, and insufficient knowledge on diet and exercise (Spanos *et al.*, 2013a:90). The caregivers need a practical, drafted diet plan (within financial constraints) of easy available healthy food items, time management skills, and training regarding the execution of the diet plan (for example, recipes) for the successful execution of the dietary intervention (Ruud *et al.*, 2016:208). To be successful in their task as supporter, the caregivers should have an optimal supportive attitude and knowledge about diet and physical activity (Spanos *et al.*, 2013a:99; Trip *et al.*, 2016:789).

### **2.4.4 Summary**

Effective intervention programmes are essential in the improvement of the quality of life of the AWID (Humphries *et al.*, 2009:176). Multi-component interventions are the gold-standard of interventions to ensure sustainable change in dietary intake and exercise in AWID (Doherty *et al.*, 2017:2; Hamilton *et al.*, 2007:344). Research studies that investigate the current situation and practice in the care centres play a critical role when developing the optimum intervention programme, but most studies lack power, control, and often a theoretical basis, in behavioural studies (Willems *et al.*, 2017:256). There is a need for qualitative research to explore the role and experiences of caregivers in intervention programmes (Ptomey *et al.*, 2017:6; Spanos *et al.*, 2013a:99). Caregiver support plays an important role in the success of sustainable intervention programmes and they need optimum support and training from the implementation team. External support by health care professionals (such as dietitians, social workers, biokineticists, and physiotherapists) for caregivers and AWID in interventions is necessary to improve the long term outcome of the intervention (Hooren *et al.*, 2002:560; Sundblom *et al.*, 2015:304).

## 2.5 Conclusion

Various researchers have found that the prevalence rate of obesity in individuals in AWID is higher than in the non-disabled population (Grondhuis and Aman, 2014:787; Maiano, 2011:189; Melville *et al.*, 2008:425; Hsieh *et al.*, 2014:851). This combination of disability and obesity can start a vicious cycle where obesity related diseases are added to the AWID causing further restrictions to an already marginalised population (Froehlich-Grobe & Lollar, 2011:542). There is a higher prevalence of multi-morbidity (where AWID are diagnosed with one or more conditions in addition to ID) in AWID compared to the non-disabled population. People with ID experience barriers in terms of accessing health care services. In fact, they are dependent on caregivers to communicate their health needs (Hamilton *et al.*, 2007:344). Furthermore, health care professionals have a lack in knowledge in the support and treatment of AWID (Bhaumik *et al.*, 2008:297; Hamilton *et al.*, 2007:344). Moreover, AWID have a low quality diet; followed by a sedentary life style, and have a low physical activity level, which increases their risk for developing NCDs (Emerson, 2011:155; Rimmer *et al.*, 2010:2). People with ID have an increased risk of being exposed to social circumstances (such as poverty, poor housing, unemployment, and social isolation) that affect health negatively (Cooper *et al.*, 2015; Emerson, 2011) and have higher prevalence rates of NCDs than the non-disabled population (Doody, 2012:2; Taggart and Cousins, 2014:9; WHO, 2016b).

Factors affecting the risk for developing overweight and obesity in AWID are changeable or unchangeable. Unchangeable factors are those related to age, severity of ID, gender, and genetic syndrome (Bhaumik *et al.*, 2008:288; de Winter *et al.*, 2012b:400; Rimmer *et al.*, 2011:1730). Changeable risk factors have a personal or environmental association (Hsieh *et al.*, 2014:852). The personal factors are: medication use (such as anti-psychotics, anti-depressants, and anti-hypertensives) (Bokszanska *et al.*, 2003:285; Cohen *et al.*, 2001:114); sedentary habits (Cartwright *et al.*, 2015:103; Dairo *et al.*, 2016:209; Draheim *et al.*, 2002:361, Mikulovic *et al.*, 2014:153); and poor dietary intake (Adolfsson *et al.*, 2008:1; Hamilton *et al.*, 2007:339; Ptomey. *et al.*, 2013:625). Environmental risk factors are concerned with the type of residence and health support. A comprehensive understanding of the role of these risks factors is essential for compiling successful intervention programmes and therefore, more research is needed (Melville *et al.*, 2007:223).

Globally, various researchers have investigated the dietary intake of AWID in countries such as the USA, UK, Italy, Sweden, and Ireland. Generally, the diet quality of the AWID is reported to be insufficient by various researchers (Adolfsson *et al.*, 2008:1; Braunschweig *et al.*, 2004:186; Cunningham *et al.*, 1990:3; Draheim *et al.*, 2007:392; Hoey, 2015:68; McGuire *et al.*, 2007:497; Ptomey. *et al.*, 2013:625) with an inadequate consumption of dietary fibre (Braunschweig *et al.*,

2004:186; Hoey, 2015:68) and high intake of SSBs and fruit syrups (Adolfsson *et al.*, 2008:1; Hsieh *et al.*, 2014:860), saturated fat (Hoey, 2015:68; Cunningham *et al.*, 1990:10), and sodium (Bertoli *et al.*, 2006:110). Overall consumption of fruit and vegetables are lower than recommendations (Adolfsson *et al.*, 2008:1; Braunschweig *et al.*, 2004:186; Draheim *et al.*, 2007:392; McGuire *et al.*, 2007:497; Ptomey. *et al.*, 2013:1)

The development of a sustainable multi-component intervention programme based on results derived from current circumstances with optimum caregiver involvement is necessary to prevent further physical disability due to secondary conditions such as DM (Beeken *et al.*, 2013:2; Cooper *et al.*, 2004:414).

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## CHAPTER 3: ARTICLE

# DIETARY INTAKE PRACTICES OF ADULTS WITH INTELLECTUAL DISABILITY

Dietary intake practices of adults with intellectual disability in a controlled care center environment

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**Abstract**

Background: High obesity prevalence among adults with intellectual disability (AWID), increases their risk for non-communicable diseases. The aim of this study was to assess the dietary intake practices of AWID in a controlled, care center environment.

Methods: A mixed-methods design, was followed. Demographic data, along with a three-day plate waste study was collected from 66 AWID. Focus group discussions were held with staff members to obtain more information on the dietary practices of the AWID.

Results: The quality of the dietary intake was low. Caregivers expressed a need for cooking skills training, menu variety and, healthier snacks.

Conclusions: The dietary intake in this study population needs improvement. Training is recommended and should be accompanied by professional dietetic input.

**Keywords**

intellectual disability; dietary practices; dietary intake; controlled environment; dietary quality; dietary diversity

Dietary practices of adults with intellectual disability in a controlled care center environment

## 1. Introduction

Prevalence rates of intellectual disability (ID) in the United States of America (USA) are between 1% and 3% of the population (Ptomey and Wittenbrook, 2015). The occurrence of ID(s) is higher in low- to middle-income countries (Maulik *et al.*, 2011) such as South Africa (SA). In SA, there is a scarcity of data regarding statistics, living conditions, and dietary intake pertaining to adults with intellectual disability (AWID) (Adnams, 2010, Foskett, 2014, McKenzie *et al.*, 2013). Overall, the disability rate in SA is 7.5% (2.87 million individuals) (Statistics, 2014).

Overweight and obesity rates are higher in AWID compared to the non-disabled population (Melville *et al.*, 2007, Rimmer *et al.*, 1995, Yamaki, 2005) and this increases the risk for developing, non-communicable diseases (NCDs) such as cardiovascular diseases (CVDs), diabetes mellitus (DM), and certain cancers (Doody, 2012, Taggart and Cousins, 2014). Poor dietary intake and a lack in physical activity in AWID are thought to have contributed to the high overweight and obesity rates in this population (Bhaumik *et al.*, 2008, Humphries *et al.*, 2009).

Due to the difficulties experienced in the dietary recording of AWID, limited research is conducted on this population (Humphries *et al.*, 2009). More information is needed on dietary intake practices in AWID to develop effective intervention programs (Humphries *et al.*, 2009, Melville *et al.*, 2007, Ptomey. *et al.*, 2013). In SA, AWID were moved (since 1997) from long-stay hospital settings to homes and care centers in communities. Most of these community homes function independently outside of the main community that they are situated in (Foskett, 2014). In 2013, the Department of Social Development in SA reported that about 149 residential facilities (managed by non-governmental organisations, and serving 7982 people with varying disabilities) received subsidies from the Government (DWCPD, 2013). The purpose of this

study was to assess the dietary intake practices of AWID in SA, in a controlled, care center environment to gain a better understanding of their dietary intake practices. This will provide valuable information for observational and intervention studies to follow.

## **2. Methods**

### *2.1 Research setting and design*

The research team used a mixed-methods sequential design for this observational study to obtain a comprehensive overview of the dietary intake practices of AWID living in two care centers, within a controlled environment, in two provinces of SA. Seventy-eight (78) AWID were recruited as part of this study. The objective was to describe the dietary intake of the AWID of these centers without comparing the dietary intake of one center to the dietary intake of the other center. The researchers evaluated the menus of the two centers separately, and compared the average dietary intake of all the participants with ID of the particular center to the menu of that center. Men and women with ID aged 18 – 40 from any cultural background were included in the study. These individuals resided in the hostels of the care centers, and were able to feed themselves. They received at least three meals a day from the center. The researchers excluded individuals who were not able to verbalise their assent in a clear manner, and/or could not stand on a scale. The legal guardians of the participants with ID had to give their consent, and the participants had to assent to participation.

Center 1 consisted of eight houses with 15 AWID, and a house mother in each, whereas at Center 2, the AWID resided in a hostel with different sections. Center 1 served three meals at 7:00, 12:00, and 17:00; and Center 2 served meals at 8:00, 13:00, and 18:00. Both centers served a midmorning snack (fruit, bread, or biscuits) at 10:00. All meals were prepared at a central kitchen from a fixed menu. Center 1 served one meal (dinner) at the houses and all the other meals at a central dining room. Center 2 served all meals in a central dining room. During

mealtimes, staff members either sat at the table or nearby to control margarine and sugar use. Caregivers plated the food according to each participant's needs. The centers served dessert once or twice a week. During the week, jelly and custard were served as dessert, and on a Sunday, fresh fruit salad with ice-cream or custard was served. At both centers, the menus were adapted according to the weekly fruit and vegetable donations received from farmers. The AWID had freedom to buy snacks from a snack shop or supermarket at given times.

The researchers recruited staff members from the two care centers for ID, included in this study, to participate in focus group discussions. The focus group participant had to be a staff member for at least one year, and know the AWID well. Moreover, the staff members could participate if they gave written, informed consent, and the manager of the care center gave permission for them to participate. The aim was to gain more information regarding the food preferences and dietary intake of the AWID, especially their snacking preferences between and after meals. The study was in line with guidelines for Ethics in Health Research as published by the Department of Health of SA and was approved by the ethics committee of the university from which the study was conducted (NWU-00070-16-S1) (Department of Health, 2015).

## *2.2 Data collection*

Demographic data, for descriptive purposes (age, gender, type of disability, smoking, alcohol intake, and medication use), was collected from the nurse of each care center.

Anthropometric measurements were done by an accredited anthropometrist according to the standards of the International Society for the Advancement of Kinanthropometry (ISAK) (ISAK, 2006). The participants were dressed in lightweight clothing (without a belt) and slip-on shoes where possible. The researchers measured the body weight and height of the AWID with a calibrated electronic scale (UWE BW – 150, 1997 MODEL, Brisbane Australia) to the nearest 0.1 kilogram (kg) and a stadiometer (Seca 264, Hamburg, Germany) to the nearest 0.1 centimetre

(cm), respectively. Lastly, the researchers measured the waist and hip circumference with a flexible, stretch resistant, steel tape (Lufkin, Cooper Tools, Apex, NC) to the nearest centimetre.

The plate waste method was used to collect dietary intake data (Jaco *et al.*, 2007, Kirks and Wolff, 1985). The researchers weighed and recorded the weight of the plated and leftover food items on the numbered plates as well as the snacks/beverages purchased by each participant for three days, during all meals and snacks. All the food items and snacks recorded were coded, and manually entered into a dietary analysis software program for analyses; FoodFinder for Windows, (SAMRC) (Langenhoven *et al.*, 2002, Wolmarans *et al.*, 2010). The mean dietary intake for three different days, over three weeks, for each participant was calculated. The Dietary Quality Index Revised (DQI-R) and the dietary diversity score (DDS) were calculated for the mean dietary intake of each participant as well as the menus of the two care centers (Haines *et al.*, 1999). Two amendments were made to the DQI-R and DDS (Haines *et al.*, 1999) according to the Food Based Dietary Guidelines (FBDGs) of SA (Vorster *et al.*, 2013). The original DQI-R and DDS evaluated grain intake, whereas the FBDGs evaluated recommended starch intake. In this study, the starchy vegetables (potatoes and sweet potatoes) were classified as starch intake and not vegetable intake, as with the original DQI-R (Vorster, 2013). The second adaptation concerned the quality of fruit and vegetable intake. In the original DQI-R, the fruit and vegetable intake were evaluated individually, whereas the FBDGs recommended a combined intake of 600 g (7.5 portions) of fruits and vegetables per day (Naude, 2013). Consequently, the combined fruit and vegetable intake were evaluated. The DQI-R uses a 100-point scale and consists of 10 different components of diet quality, scored from 0 to 10 (Haines *et al.*, 1999).

Three semi-structured focus group discussions were performed by experienced researchers in the field of nutrition with the staff of the care centers after which data saturation was reached.

### 2.3 *Quantitative statistical analysis*

Sixty-six (66) of the seventy-eight (78) participants were eventually included in this study: three individuals were excluded because they did not meet the inclusion criteria and the dietary data of nine participants were incomplete. Statistical power was calculated making use of *a priori* power analysis using the software package G\*Power 3.1.9.2 for Windows (Faul *et al.*, 2007). A sample size of 58 would have been sufficient to detect an effect size of 0.35 with a power of 80% and an alpha of 0.05. Descriptive statistics were done using SPSS, version 24 (SPSS, Chicago, IL, USA). Statistical significance was set at  $p \leq 0.05$ . The distribution of the data was assessed and the researcher reported descriptive statistics variables as means  $\pm$  standard deviations, and categorical variables as frequencies and percentages.

### 2.4 *Qualitative statistical analysis*

Qualitative data from the three focus group discussions were recorded, transcribed, and then coded using the software program ATLAS.ti 8.0. The qualitative data were analysed using an axial coding process of deductive and inductive codes. The codes were grouped into categories/themes (Saldana, 2009). The final steps were to group the codes in hierarchical clusters using factor analysis. Triangulation from theory, and the quantitative data were used to select meaningful clusters (Henry *et al.*, 2015).

## 3. **Quantitative results**

Thirty-eight (57.6%) male and 28 (42.4%) female individuals were included in the study. Of the 66 participants, 18 (37.3%) were diagnosed with Down Syndrome (DS). The data indicated that 57.6% of the participants were on medication (male: 18.2% and female: 39.4%). Table 3-1 represents the descriptive statistics of the population.

**Table 3-1**      **Descriptive statistics**

Variable	Total mean (SD)	Gender means (SD)	
		Male	Female
Age (years)	32.4 (6.1)	32.2 (6.1)	32.6 (6.1)
Alcohol use and smoking	None	None	None
Waist circumference (cm)	90 (15.6)	88.7 (12.0)	91.7 (19.6)
Hip circumference (cm)	107.9 (16.0)	102.5 (10.8)	115.3 (19.0)
Body mass (kg)	79.0 (21.2)	77.6 (17.1)	80.9 (25.9)
Stature (cm)	163.4 (11.3)	169.0 (9.8)	155.8 (8.3)
BMI (kg/m <sup>2</sup> )	29.8 (8.1)	27.3 (6.3)	33.1 (9.1)
Waist/hip ratio	0.83 (0.06)	0.86 (0.47)	0.79 (0.06)

*cm, centimetre; kg, kilogram; BMI; Body mass index*

### 3.1 Dietary intake of adults with intellectual disability

Table 3-2 represents the dietary intake of the AWID in grams to give an overview of their intake compared to guidelines. The total dietary intake of energy, carbohydrates, and fibre were lower, and the total dietary intake of fat and saturated fat were higher than recommendations.

**Table 3-2** Dietary intake of adults with intellectual disability

Nutrient	Male	Recommended	Female	Recommended
	Mean Intake		Mean Intake	
Energy (kcal)	2377.4 (244.4)	2605 <sup>a</sup>	1875.9 (205.5)	2079 <sup>a</sup>
Total Protein (g)	78.5 (8.0)	65-97 <sup>b</sup>	64.2 (8.6)	52-78 <sup>b</sup>
Total fat (g)	108.2 (14.5)	58-101 <sup>b</sup>	82.7 (9.5)	46-81 <sup>b</sup>
Saturated FA (g)	34.5 (3.9)	≤ 29 <sup>b</sup>	27.1 (4.9)	≤ 23 <sup>b</sup>
MUFA (g)	40.5 (5.4)	28.8 <sup>b</sup>	31.4 (3.2)	21.9 <sup>b</sup>
PUFA (g)	24.7 (6.8)	17-29 <sup>b</sup>	17 (3.0)	14-23 <sup>b</sup>
TFA (g)	2.3 (1.0)	≤ 2.9 <sup>b</sup>	1.6 (0.9)	≤ 2.3 <sup>b</sup>
CHO (g)	255.0 (26.3)	357-486 <sup>b</sup>	206.5 (26.0)	259-388 <sup>b</sup>
Dietary fibre (g)	16.1 (3.2)	25 <sup>b</sup>	11.8 (1.7)	25 <sup>b</sup>
DQI-R	52.7 (4.0)	Maximum 100	46.6 (4.0)	Maximum 100
DDS	2.7 (0.8)	Maximum 10	2.0 (0.5)	Maximum 10

<sup>a</sup>, World Health Organization, 2003; <sup>b</sup>, Scientific Advisory Committee on Nutrition, 2011

kcal, kilo calorie; g, gram; FA, Fatty acids; MUFA, Monounsaturated fatty acids; PUFA, Polyunsaturated fatty acids; TFA, Trans fatty acids; CHO, Carbohydrates; DQI-R, Dietary Quality Index Revised; DDS, Dietary diversity score

### 3.2 Dietary Diversity Score (DDS) and Dietary Quality Index Revised (DQI-R)

The maximum total score for DDS is 10. The resulted DDS of the ID men and women across the care centers indicated a low diversity in dietary intake (Table 3-2). The mean DQI-R for the ID men and women indicated vast room for improvement in overall dietary quality (Table 3-2).

### 3.3 Comparison of the Food Based Dietary Guidelines (FBDGs) and actual dietary intake

Table 3-3 represents the macronutrient intake of the ID participants compared to the revised FBDGs of SA (Steyn and Ochse, 2013, Vorster *et al.*, 2013). Dietary intake of total fat and saturated fat were substantially higher than the recommended normal intake. The dietary intake of carbohydrates was lower, and the dietary intake of added sugar was slightly higher than recommended.

**Table 3-3: Total dietary intake compared to the Food Based Dietary Guidelines of South Africa**

<b>Nutrient intake /day</b>	<b>FBDGs</b>	<b>Males (n=38)</b>	<b>Females (n=28)</b>
Meat intake (g)	Meat intake limited to 90 g/day	208.0	175.0
Carbohydrate (%)	50% of TE	43.1	44.2
Added sugar (%)	< 10% of TE (< 6% of those at risk)	10.2	11.6
Total fat (%)	20%–30% of TE	41.1%	39.8%
SFAs (%)	≤ 10% of TE (≤ 7% of those at risk)	13.1	13.03
PUFAs (%)	6-10% of TE	9.4	8.2
TfAs (%)	≤ 1% of TE	0.9	0.8
Sodium (mg)	< 2000 mg/day	2770.1	2151.8
Fruit and vegetable (g)	600 (7.5 portions of 80 g each)	164.0	118.0

*SFAs, Saturated fatty acids; PUFAs, Polyunsaturated fatty acids; TfAs, Trans fatty acids; g, gram; FBDGs, Food Based Dietary guidelines; TE, total energy intake; n, number of participants*

### 3.4 *Snack choices of participants*

The AWID at both centers had the opportunity to choose and pay for their own snacks at a local supermarket once a week, and the snack shop of Center 1 retailed for approximately 10 minutes after lunch, Mondays to Saturdays. Table 3-4 lists the top 10 snack or drink choices made at the snack shop and supermarkets by the AWID, at both centers, based on frequency.

**Table 3-4**      **Top 10 snack choices of the adults with intellectual disability**

<b>Snacks and drinks</b>	<b>n</b>	<b>%</b>
1 Salted crisps, potato/corn (36 g, 100 g, 125 g)	23	34.8
2 Carbonated cool drink (340 ml/500 ml/1000 ml)	12	18.2
3 Diet carbonated cool drink (340 ml/500 ml)	9	13.6
4 Peanuts (50 g)	5	12.1
5 Mixed Sweets	4	6.1
6 Lollipop	4	6.1
7 Chocolate (85 g)	3	4.5
8 Diabetic or diet chocolate	2	3.0
9 Fruit juice (340 ml)	1	1.5
10 Energy bar	1	1.5

*n*, number of participants buying; *ml*, millilitre; *g*, gram; *%*, percentage of participants buying

### 3.5 *Comparison between individual dietary intake and the menu*

A one-sample *t*-test determined whether or not the mean DDS and DQI-R of the participants were different from the DDS and DQR-R of the menu of the center that they reside in (Table 3-5). The mean DDS and DQI-R for the 46 participants of Center 1's dietary intake were statistically significant higher than the mean DDS and DQI-R of the set menu of that center

( $p \leq 0.05$ ) (Table 3-5). Only the DQI-R for the ID men in Center 2 was statistically significant higher than the DQI-R of the menu ( $p \leq 0.05$ ) (Table 3-5).

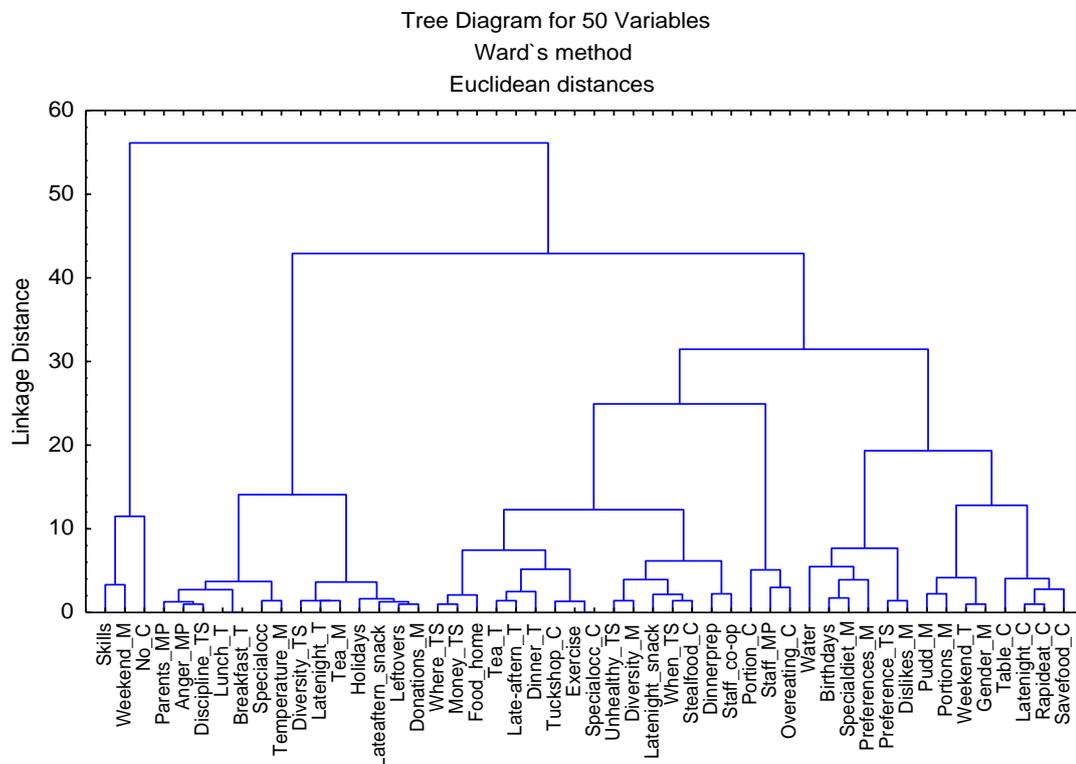
**Table 3-5 Mean DDS and DQI-R scores for the menus and dietary intake in Center 1 and Center 2**

Variables	Mean (SD)	Effect size		
<b>Center 1</b>	DDS menu (35 days)	1.85 (0.74)	1.04	
	DDS dietary intake (n = 46 )	2.13 (0.27)*		
	<b>Male participants</b>			
	DQI-R menu (35 days)	41.76 (14.95)	2.54	
	DQI-R dietary intake (n = 24)	51.98 (4.03)*		
	<b>Female participants</b>			
	DQI-R menu (35 days)	37.60 (13.77)	2.08	
	DQI-R dietary intake (n = 22)	45.15 (3.63)*		
	<b>Center 2</b>	DDS menu (7 days)	2.68 (0.68)	0.05
		DDS dietary intake (n = 20)	2.74 (1.26)	
<b>Male participants</b>				
DQI-R menu (7 days)		50.14 (8.86)	0.94	
DQI-R dietary intake (n = 14)		53.83 (3.94)*		
<b>Female participants</b>				
DQI-R menu (7 days)		45.84 (8.68)	0.79	
DQI-R dietary intake (n = 6)		49.19 (4.24)		

\* $p \leq 0.05$  indicate statistical significant difference between the DDS or DQI-R of the dietary intake and the DDS or DQI-R of the menu. Data presented as mean (standard deviation) DDS, Dietary diversity score; DQI-R, Dietary quality index Revised; SD, standard deviation

**4. Qualitative results**

Four themes emerged from the focus group discussions: menu at the centers; other eating occasions not included in the menu (such as birthdays, special occasions, and late-night snacking); snacks from the snack shop and/or supermarket; and control over food intake. The latter included individuals' own self-control as well as the control of the care takers over the individuals' food intake. The Dendrogram in Figure 3-1 presents the codes (horizontal axis) arranged in clusters that have structural associations.



**Figure 3-1: Dendrogram showing the clustering of 50 codes with Ward's hierarchical clustering method**

#### 4.1 *Menu at the centers*

The menu at centers theme describes food intake and preparation activities related to the menu. The menu of Center 1 was a five-week cycle menu with different cooked porridges during the week, eggs on Saturdays, and a cereal on Sundays for breakfast, with bread as an ever-present accompaniment. The menu at Center 2 was a seven-day cycle with a mainly protein-based breakfast. At both centers, the main meal was served at lunchtime. At Center 1, the same type of meat was not served on specific days of the week, but altered during the seven-day week. At Center 2, the same type of meat was served on specific days. At Center 1, largescale cooking equipment was used, but at the smaller Center 2, household gas stoves were used to prepare food. Overall portion sizes were bigger for the men than the women. The focus group members reported the portion sizes to be more than sufficient, but complained about the variety not being sufficient, and the cooks using too much oil and sugar in their cooking.

#### 4.2 *Other eating occasions not included in the menu*

The other eating occasions not included in the menu theme denotes occasions such as late-night snacking, birthdays, and parties. Birthdays were special occasions at both centers. Sometimes, the parents would send a cake or the care givers would bake a cake and have a birthday party with cool drink, cake, and ice cream. Some residents would bring food (fruit, juice, and yogurt) from home. Year-end parties entail a barbeque with a dance. The men were more inclined to ask for bread as a late-night snack.

#### 4.3 *Control over food intake*

At one center, internal staff co-operation was lacking because they did not follow the same rules throughout. For example, some staff members will serve larger portions than others, and give the AWID bread as a late-night snack, where other staff members will do the opposite. Some of the AWID made use of these inconsistencies, manipulating the more lenient staff

members by, for instance, telling the staff member that their parents said they could have it.

Staff members mentioned that some AWID are eating too fast or too much, therefore, unable to control their dietary intake. During holidays, birthdays, weekends, special occasions, and after 19:00 when the caregivers retired for the night and participants had access to food, control over food plating and intake was less, leading to increased food intake.

#### 4.4 *Snacks/drinks bought at snack shop and/or supermarket*

The main choices from the snack shop or supermarket were salted crisps, cool drink, and chocolates. Some of the AWID will buy juice and yogurt. One center disciplined residents for bad behaviour by not allowing the purchase of snacks. The snack shop at Center 1 did not have healthy snack options available, but the residents had freedom of choice choosing their snacks. Focus group members made suggestions for healthier options such as fresh fruit, dried fruit, and yoghurt.

## 5. Discussion

This research study investigated the dietary intake practices of AWID in a controlled, care center environment. Notwithstanding the controlled environment, the mean BMI for the men and women were indicative of being overweight and obese, respectively. The eating behaviour of the study population may have had an influence on their weight status. The focus group discussions with staff revealed that some AWID display behaviour of continual eating/drinking and eating too fast. Bhaumik *et al.* (2008) reported similar behaviour displayed by 4% of AWID:

*“You know, they will eat, and eat, and eat, and eat...”*

*“The pie is so hot, but they eat so fast”*

*“So I tell them to eat slower, we have enough time.”*

The mean energy intake in this study population of  $2164.6 \pm 33.7$  kcal/day was higher than reported by two community-based studies on AWID, which were  $1472 \pm 458$  kcal/day and  $1928 \pm 891$  kcal/day (Bertoli *et al.*, 2006, Ptomey. *et al.*, 2013), but was lower than an earlier, controlled, long-stay hospital setting study in SA , which was 2527.7 kcal/day (Molteno *et al.*, 2000). In fact, total energy (TE) intake in this current study was lower than recommendations (Scientific Advisory Committee on Nutrition, 2011). This observation does not correspond with the overweight and obesity rates in this study population, and a possible reason could be that the dietary data did not include all eating occasions (as confirmed by the qualitative data) such as birthdays; late-night snacking; special occasions; weekends and holidays.

*“This is the time that they will take crisps out of their closets and eat when they go to bed at 9 pm during the week and 10-11 pm during weekends...”*

The macronutrient distribution range in this study (43.8% carbohydrates; 13.6% protein; and 40.1% fat) compared well with another study done in a long-stay institution in Ireland (39% carbohydrates; 18% protein; and 43% fat) (Cunningham *et al.*, 1990). One concern is that the percentage of fat intake in this current study population exceeds recommendations and is higher than various other studies done on AWID (30.4% to 31% of TE) and that of the non-disabled population in SA (Adolfsson *et al.*, 2008, Bertoli *et al.*, 2006, Molteno *et al.*, 2000, Smuts and Wolmarans, 2013). The caregivers reported high fat foods, such as pies, hamburgers and crisps, as favourite foods of the AWID. Moreover, food preparation may have had an effect on the high dietary fat intake (43% fat of TE) of the ID participants in this study:

*“Personally, I do not like fatty food, I cannot handle it when the dish stands there and you can see the oil...”*

Staff members in focus group discussions indicated that the cooks are using unhealthy cooking and food preparation methods:

*“They are inclined to add oil to already high fat meats, frying them...”*

Caregivers in the discussions recommended that the cooks should go for training in cooking skills:

*“Training must be better.”*

Ptomey *et al.* (2013) made a similar observation about the need for training in cooking skills.

Equally, saturated fat intake in this current study population, was higher than the recommended intake. Another factor that could have affected the saturated fat intake is the high dietary consumption of meat (208 g /day and 175 g / day for ID men and women respectively) in this study population. In fact, the caregivers in the focus group discussions mentioned that the favourite food of the ID residents at both centers was ‘braaivleis’ (a traditional way of having barbequed meat).

Despite the high intake of meat in this study population, the total protein intake was within recommendations (10% to 15% of total energy) (WHO and FAO, 2003). A possible reason could have been the lower intake of carbohydrates and the consequently lower contribution of plant-based proteins to the overall protein intake. The lower carbohydrate intake (less than 50% of total energy) mirrors the dietary trend in typical white, coloured, and Indian South Africans, where the dietary intake of carbohydrates is under 50% and that of added sugar above 10% of TE intake (Steyn, 2006, Vorster, 2013). In an Irish dietary study on AWID, only 2.3% of the participants consumed less than 10% of TE from sugar (Hoey, 2015). The dietary fibre intake in this current study population (16.1 g/day and 11.8 g/day for men and women, respectively) was less than half of the recommendations (> 25 g/day). This is a reflection of low dietary fibre intake by AWID around the world (Adolfsson *et al.*, 2008, Hoey, 2015, Ptomey. *et al.*, 2013, Ptomey and Wittenbrook, 2015) and in the non-disabled population in SA (Vorster, 2013). In this current study population, the focus group discussions revealed that the AWIDs’ favourite foods and snacks (pies, hotdogs, potato salad, crisps, and cool drink) are those low in fibre. Fortunately, there was a need expressed for healthier snacks options:

*“My opinion is that there are so many unhealthy options, they need healthier options like dried fruit and so...”*

Low fibre intake is a concern, because minimally processed starchy foods such as grains, legumes, and root vegetables (for example, sweet potatoes and beetroot) and fruit play an important role in the prevention of NCDs (Baiao *et al.*, 2017, Vorster, 2013). One way of increasing dietary fibre intake is to include dry beans and lentils in the diet (Venter *et al.*, 2013). The participants in this study had no intake of legumes, since neither care centers offered it as part of their menu.

The FBDGs of SA recommend added sugar in the diet not to be more than 10% of TE, but those at risk should not have more than 6% of TE intake. People at risk to the harmful effects of sugar are those who are overweight, have pre-diabetes, and those who do not consuming fluoride on a daily basis through toothpaste or water (Temple and Steyn, 2013). In this study, the ID participants had an added sugar intake slightly higher than 10% of TE intake. It should be noted that the participants are at risk to the harmful effects of sugar due to the high prevalence of overweight and obesity, and should decrease their added sugar intake to less than 6% of TE per day (Temple and Steyn, 2013). In the focus group discussions, it was clear that the cooks add too much sugar to the food:

*“One thing I know you will agree to, there is too much sugar and margarine in the food, in the porridge, in everything.”*

The participants had the freedom of buying their own snacks and/or drinks at a snack shop or supermarket nearby, which added to their high sugar intake. Researchers found that when AWID have freedom of choice, they have an increased risk for obesity due to unhealthy food choices, which leads to having an increased sugar intake (Adolfsson *et al.*, 2008, Draheim *et al.*, 2007, Hove, 2007). The staff members complained about not having a say in the snack choices of the AWID:

*“We do not have any control over that. We cannot, we are not allowed, to tell them what they have to buy at the snack shop.”*

Similarly, poor food choices are clear when investigating the items chosen by participants as snacks. The most popular snack choice was salted crisps followed by carbonated cool drink.

*“Because it is Cola, it is cool drink and crisps and chocolates...”*

A meta-analysis concluded that the intake of free sugar or sugar sweetened beverages (SSBs), resulted in increased energy intake and consequently, increased body weight (Te Morenga *et al.*, 2012). The snack variety at the snack shop is low and consists of unhealthy, high sugar, and high fat snacks. Consequently, the AWIDs’ choice of snacks is limited:

*“They do not have much variety. My honest opinion is that there are unhealthy snacks and I feel they can add healthier options.”*

*“It is cool drink, crisps and chocolate. It is not about specific flavours.”*

Nevertheless, some of the AWID at the care centers did buy healthy snacks from the supermarket and would prefer healthier snacks:

*“Sometimes they will buy yogurt or fruit or dried fruit ...”*

*“So they want to buy something else.”*

*“Yes, I have two that would like yoghurt and fruit.”*

Although sodium intake by the participants in this study was higher than recommendations, there were no additional salt available at the tables to add to their meals. In a USA study, 87, 3% of the AWID consumed more than the daily recommended sodium intake. Dietary records showed that these ID individuals consumed high amounts of prepacked meals like chicken nuggets, frozen pizzas, boxed pasta meals, and tinned vegetables (Ptomey. *et al.*, 2013). Dietary intake studies in the non-disabled population in SA have found the sodium intake to be between 2400 mg and 4400 mg per day (Wentzel-Viljoen *et al.*, 2013). The increased intake of salt leads to an increase in blood pressure, which is a strong risk factor of CVD,

coronary heart disease, and stroke (Wentzel-Viljoen *et al.*, 2013). In fact, significant sources of sodium are available at the care centers, including processed foods such as processed meat sausages, luncheon meats, and pies.

*“We are inclined to say; ok it is sausages again... because it is sausages and cold meat that is the food for supper.”*

Additionally, the most popular snack shop snack, for the participants in this study, was salted crisps, which is high in sodium.

Unfortunately, the fruit and vegetable intake of the ID participants were substantially lower (144 g per day) than the FBDGs’ recommendations of 600 g/day. An ID study done in the USA, found a negative association between fruit and vegetable intake and weight. As the participants’ body weight increased, the fruit and vegetable intake decreased (Ptomey. *et al.*, 2013). Similarly, in a systematic literature review, it was concluded that AWID have an inadequate intake of fruit and vegetables (Humphries *et al.*, 2009). Equally, low fruit and vegetable intake is observed in the typical South African population (Naude, 2013). Evidence found in systematic literature reviews and health reports made it clear that an increased intake in fruits and vegetables may reduce the risk of developing NCDs (Naude, 2013).

The staff members of Center 1 complained about a lack in menu variety:

*“The menu is always the same.”*

The staff members’ observation was in line with the low DDS of the menu and dietary intake of Center 1. Similarly, a cross-sectional study representing adults in SA, had a overall low DDS (4.02) (Labadarios *et al.*, 2011). The three-day dietary intake of the participants was compared to the menus. The DDS and DQI-R of the three days’ dietary intake of the participants and the DDS and DQI-R of the menus were significantly different from one another. This was more so for Center 1 than for Center 2. A possible reason for this difference is that the menu was adapted

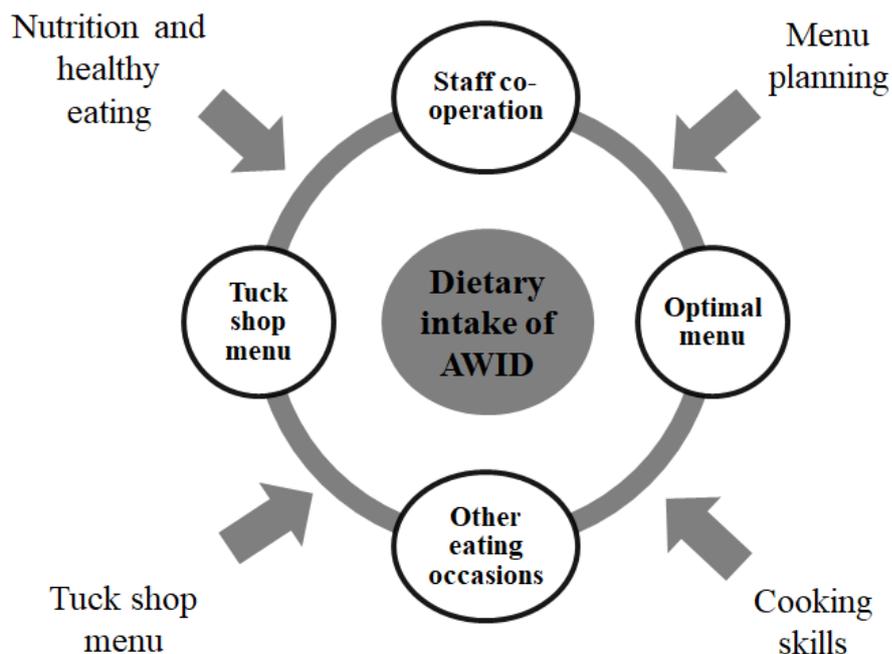
according to the weekly fruit and vegetable donations received from farmers and market availability.

*“We have a man from Brits; he is a farmer who donates vegetables on weekly bases. He was here this morning, donating vegetables. It is vegetables in season like, tomatoes, lettuce, cucumber, cabbage...”*

The mean DQI-R of the three-day dietary intake was  $49.8 \pm 5.2$  from a possible score of 100. In a recent South African study in typical adolescents, a higher DQI-R was reported ( $58.3 \pm 9.85$ ) (Tee *et al.*, 2015). Investigating the components of the DQI-R (intake of fat, saturated fat, cholesterol, calcium, iron, fruit, vegetable, starch, dietary diversity, and moderation) it is clear why the DQI-R is low in this study population.

The overall diet quality of the AWID in this study population needs improvement and mirrors findings in other studies with similar populations (Bertoli *et al.*, 2006; Hoey, 2015; Humphries *et al.*, 2009; Ptomey *et al.*, 2013). The results from the qualitative findings provided valuable input as to what the current situation is and how to improve it (Figure 2). Figure 2 shows the different components that have an effect on the overall dietary intake in this study population, as derived from the qualitative and quantitative findings.

On a micro-level, the objective would be to improve the dietary intake of AWID and prevent NCDs by changing the macro-level and environment by means of training the members of staff at care centers on several issues (Figure 3-2).



**Figure 3-2** Schematic representation of how education and training will improve the dietary intake of the study population

The first component to address is improved staff co-operation, where nutrition knowledge and communication between the caregivers may improve control and support so as to change the unhealthy habits of the AWID (Spanos *et al.*, 2013a). Researchers recognise the supportive role of the caregiver (Bergstrom *et al.*, 2013). Two other components are an optimal menu (including a special diet menu) and a healthy snack shop menu that complies with the most recent dietary guidelines. In addition, a recent study found an association between meal planning and food variety, food quality, and lower rates of obesity (Ducrot *et al.*, 2017). Lastly, the fourth component includes other eating occasions such as parties, birthdays, and year-end functions. These four components do not function in isolation, but affect one-another. The researchers developed Figure 3-2 by triangulating the clusters, theory, and qualitative data (Henry *et al.*, 2015).

## 6. Conclusion and recommendations

This research identified gaps in the training of staff members such as menu planning and cooking skills, which were of a poor standard. The topics recommended for training of staff members are menu planning, nutrition, healthy eating habits, and cooking skills. For the AWID, training in healthy eating habits and gaining understanding of the role healthy eating habits plays in disease prevention and weight control measures, are recommended. Some of the ID residents lack knowledge in making healthy food choices and run the consequent risk of being obese. Adults with ID should receive continuous guidance and motivation from the caregivers in making healthy food choices and cultivation of good eating habits. Consequently, the investment in caregiver training will prove to be invaluable to the overall health of the AWID.

Legumes improve the overall quality of the diet, protect against NCDs, are cost-effective, and will be the ideal food item to include in the menus of the care centers. The snack shop should be a healthy extension of the main menu at the care centers. Healthy snack suggestions are fresh fruit, yogurt, nuts, tuna or chicken salads, and healthy sandwiches or wraps. The goal of the snack shop should be to educate the AWID to make healthier snack choices when they visit the supermarket. The care centers would benefit from professional help in the planning of nutritious menus (main menu, special diet menu, and snack shop menu) to meet the most recent dietary standards and daily recommended intakes. Education on healthy eating habits for the AWID, as well as training of the caregivers on healthy food selections, will greatly add to the effectiveness in creating an environment for positive change.

One limitation was that focus group discussions could have been extended to the AWID to obtain more information regarding their food and snack preferences.

**Further research**

Due to the need for research in AWID, especially in SA, a similar study involving more care centers would provide valuable insights in the dietary intake of AWID in SA. Additionally, there is a need for further research in the implementation of programs that focus on the training and the education of staff and AWID, and consequently, observations to evaluate the outcomes.

**Conflict of interest statement**

There are no conflicts of interest or financial disclosures for any author of this manuscript. Furthermore, this research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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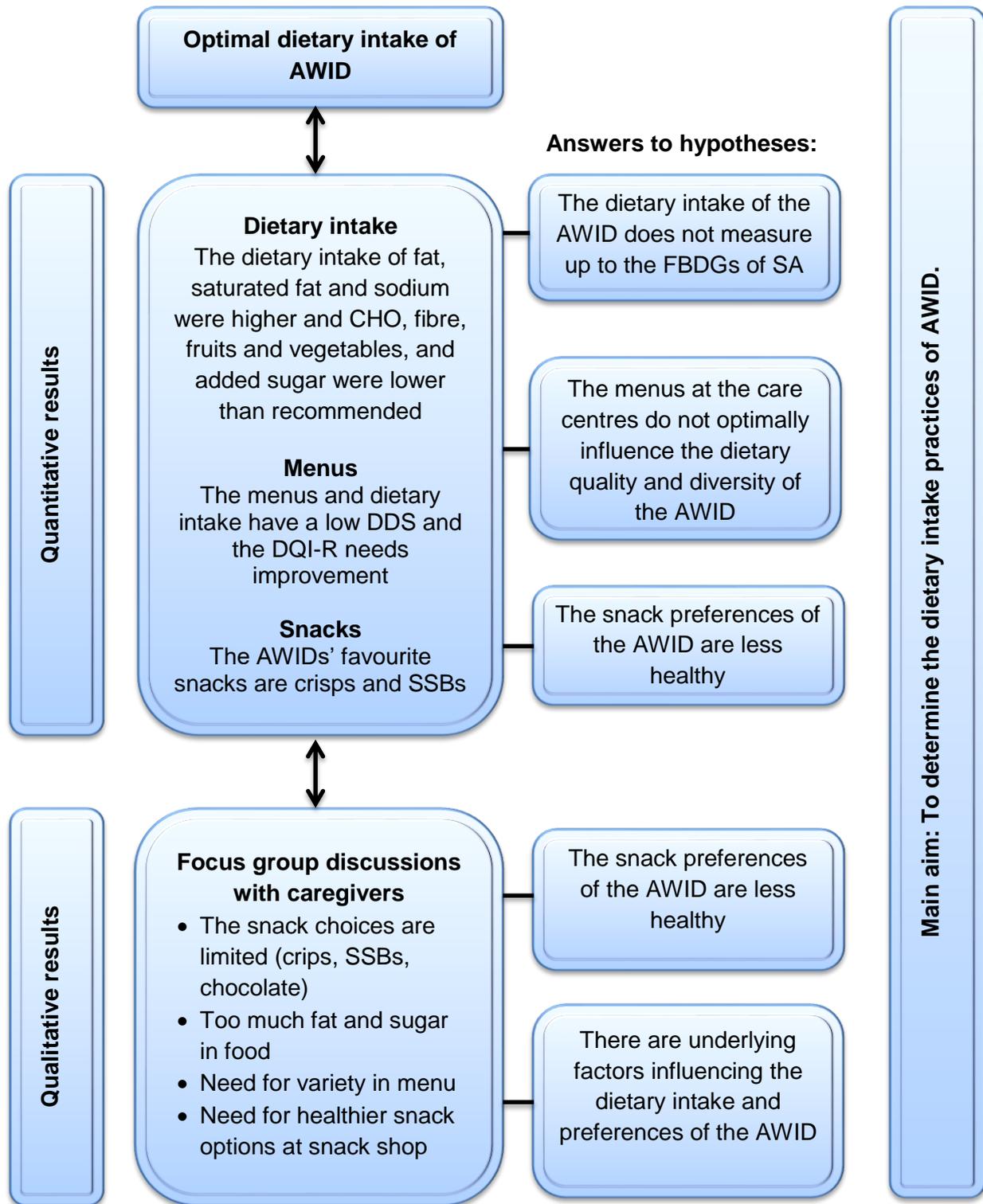
## CHAPTER 4: CONCLUSIONS AND RECOMMENDATIONS

### 4.1 Introduction

Chapter 4 is the final chapter with the purpose of summarising the findings, and drawing conclusions, grounded on the hypotheses of the study.

Figure 4.1 presents a conclusive framework of the findings of the study. The dietary intake of the AWID has an effect on their overall health and wellbeing. By means of concurrent triangulation of the qualitative and quantitative findings, it is found that the nutritional intake of the AWID at the two care centres is not sufficient according to the FBDG of SA. They have a low dietary diversity, and the quality of their diet, with high intake of fat and sugar, is poor and needs improvement. Various factors influence their dietary intake. These factors range from lack of control from the caregivers to guide them in eating healthily, to the lack of expertise in healthy cooking methods and menu planning by the kitchen staff. The menu, that should provide the basis of healthy eating, is not adhered to and does not comply with the recommendations of the FBDGs of SA. Another concern is the unhealthy environment with regards to snack choices. Not only are the snack choices provided limited, no healthy snack options are available at the snack shop. Finally, other issues that add to the dietary intake is that some of the AWID eat too fast and/or eat too much food at a time; this can be problematic during times when the caregivers have less control such as during birthdays, parties, holidays, and weekends when portion control is less.

Furthermore, Chapter 4 presents recommendations for possible further research options and the limitations of this research study.



AWID, Adults with intellectual disability; FBDGs, Food Based Dietary Guidelines; SA, South Africa; DDS, Dietary diversity score; DQI-R, Dietary quality index revised; SSBs, Sugar sweetened beverages

Figure 4-1: Conclusive framework of the findings of the study

## **4.2 Main findings according to hypotheses**

### **4.2.1 Hypothesis 1: The dietary intake of the AWID in the two care centres does not measure up to the FBDGs of SA**

The dietary intake of fat, saturated fat, added sugar, and sodium measured by the three-day food wastage data collection phases are shown to be higher than the recommendations made by the FBDGs of SA. It is of great concern that the total dietary fat intake of the AWID in this study is 40.1%, compared to the recommended 20% to 30% of TE intake. Moreover, the dietary intake of CHO, fibre, fruits and vegetables are lower than recommended. The dietary intake of PUFAs and TFAs, however, are within guidelines.

The researcher calculated the DQI-R and DDS of the dietary intake of the ID adults, and adapted the measurements according to the most recent FBDGs of SA. The DDS is below 4, which indicates a low dietary diversity. Additionally, the DQI-R ( $49.8 \pm 9.85$ , out of a maximum 100), indicates vast room for improvement.

The insufficient and excessive consumption of various key dietary components in this research study is in line with observations made by other researchers globally. Most of these observations are made in ID adults in community residences that have more freedom of choice. The qualitative data in this study provided the underlying reasons for the insufficient dietary intake, which are unhealthy cooking methods, use of processed meat, high fat food preferences (such as pies, hamburgers, and crisps), and a lack in menu variety.

Despite the PUFAs and TFAs intake that falls within the guidelines, the overall dietary intake of the AWID does not measure up to the FBDGs of SA. Hypothesis 1 is, therefore, accepted.

### **4.2.2 Hypothesis 2: The snack preferences of the ID adults in the two care centres are less healthy**

The most popular snack choices recorded are crisps and sugar sweetened beverages (SSBs) drinks. Crisps are high in sodium and SSBs are high in sugar. Consequently, both crisps and SSBs contribute to an increased risk for the development of NCDs. The AWID at Centre 1 have a limited snack choice at the snack shop, and there are no healthy snack options available. At Centre 2, there is no snack shop, but the AWID are accompanied by a caregiver on Mondays to a nearby supermarket to buy snacks. There are some AWID (at both centres) that prefer to buy healthier snacks such as yoghurt and fruit at the supermarket. Notwithstanding the latter, most of the ID adults do not realise the effect of unhealthy food choices on their health, and need to be educated on that so that healthy food and snack choices are made.

Most of the AWID make less healthy snack choices and, therefore, the hypothesis is accepted.

#### **4.2.3 Hypothesis 3: The menus at the care centres do not optimally influence the dietary quality and diversity of the AWID**

Both the DDS and DQI-R calculated for the cycle menus as well as the actual three-day dietary intake of the AWID is low, indicating an overall poor dietary variety and quality intake. There is a significant difference between the DDS and DQI-R of the menus, and of the actual mean dietary intake of the AWID, which indicates that the menus are not followed. Menus at the two care centres are adapted on a weekly basis according to the fresh fruit and vegetables donations received from farmers. Consequently, the person in charge of the menu alterations needs training in menu planning so that sound alterations can be made to the menu, without compromising it.

The care centres need the professional input of dietitians/nutritionists to compile menus that comply with recommendations. These menus need to be adapted according to the most recent dietary recommendations of the FBDGs of SA and they need to be adhered to. Legumes should also be included in the main menus of the care centres to improve both the DDS and DQI-R without causing financial constraints. Additionally, the researcher recommends the compilation of a healthier snack shop menu and special diet menu.

Therefore, the hypothesis is accepted, which means that currently the menu does not influence the DDS and DQI-R of the dietary intake of the ID adults optimally.

#### **4.2.4 Hypothesis 4: The health workers have little say to help guide the ID adults towards healthier choices**

The outcome of the quantitative data collected in this study shows that the dietary intake of the AWID is mostly not according to the FBDGs of SA, but the qualitative data collected through focus group discussions confirms the latter, and the possible reasons behind it. The caregivers complained about some of the AWID that eat too fast, and too much food and snacks. The caregivers have no control over AWID's snack purchases or intake. It is clear that health care workers at the care centres should be involved, on an ongoing basis, to influence the AWID in making healthier choices. This can be done through education in healthy food choices and the reasons why it is important. More so, the snack shop can be used as a tool to train the AWID in making healthier snack choices, by providing healthier snack options to the AWID.

Thus, hypothesis 4, that health care workers have little say to help guide the ID adults, is accepted.

### 4.3 Conclusions

People with ID are a marginalised population in SA, and research on all areas of food intake and nutrition are lacking. In these two care centres, the researcher observed that the menus were lacking in both quality and variety. The menus could be substantially improved by increasing the portions and variety of vegetables. Only Centre 2 served fruit at the 10:00 snack, which can be a healthy alternative to the bread and biscuits served at Centre 1. Additionally, the meat portions can be decreased by adding legumes in dishes. Legumes are cost effective and will lead to an increased fibre intake by the AWID. The menus were not followed due to adaptations made according to donations, which caused the diet variety and quality of the menu to not correspond with that of the individuals' actual intake. Consequently, the dietary intake of the AWID at the care centres also did not comply with recommendations of the FBDGs of SA. A well-planned menu is essential as it serves as a basis for a high quality dietary intake and variety. Additionally, the preparation of the meals was not according to healthy cooking methods and, therefore, the training of cooks was identified as a need. At Centre 1, there was a lack of cooperation amongst the caregivers that can be improved through training and improved communication. Overall, there was a lack in guidance (and training) to care centres from governmental organisations and interest groups such as healthcare workers.

Furthermore, the snack choices of the AWID were unhealthy, and there were no healthy snacks available at the snack shop. The snack shop should be a healthy extension of a well-planned menu. The AWID should be trained in how to make healthy food/snack choices and why healthy eating is important. Additionally, the caregivers should be allowed to guide the AWID in making healthy snack choices. A snack shop menu with healthy wraps and sandwiches, yoghurt, nuts, and fruit is necessary to assist in good food/snack choices. Finally, continuous professional input of health care professionals (dietitians and/or nutritionists) in the compilation of menus and the training of staff and AWID is necessary for sustainable change.

### 4.4 Recommendations for future research

This research study exposed further gaps that researchers can only answer through new research initiatives:

- It is recommended that a similar study involving a representative number of care centres in a specific province in South Africa be conducted to obtain representative data, and a better view of the dietary intake practices of AWID in the specific province. The ideal would be to conduct a national study, but due to financial constraints (South Africa is a low- to middle-

income country) the researcher recommends research on a provincial level until all provinces in SA are covered.

- It is recommended that researchers may use information gathered through this observational study to develop an intervention program, followed by a pilot study to validate the program in a chosen province. Information gained through an intervention study may be used to pave the way in providing dietary guidelines and, consequently, the monitoring of dietary practices in care centres and other residential facilities for ID adults in SA.

### **4.5 Limitations of this study**

Despite the fact that the sample size of this study was sufficient according to the *a priori* analysis, the researcher would have expected better results if more care centres were included in the study. In this current study, focus group discussions could have been extended to the AWID themselves to gather more information regarding what they consider to be healthy food and snack choices. Additionally, more information regarding their food and snack preferences, and their knowledge of healthy eating could be obtained. Another improvement on this study would be to compare the dietary intake of the AWID in care centres, in a controlled environment, with AWID who live independently. Finally the FBDG of SA is not validated for this population. For this reason a national study to validate the guidelines for this population will be of great value.

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## **ANNEXURE A: ASSENT AND CONSENT FORMS**

### **Assent form for adults with intellectual disability (AWID) participating in study**

#### **Dietary intake practices of adults with intellectual disability in a controlled care centre environment**

**REFERENCE NUMBERS:** NWU-00070-16-S1

**PRINCIPLE INVESTIGATOR:** Dr Chrisna Botha-Ravyse

**STUDENT INVESTIGATOR:** Sanet Dreyer

**ADDRESS:** North-West University, Vaal Triangle Campus

Hendrik van Eck Boulevard

Vanderbijlpark

1911

**CONTACT NUMBER:** (016) 910-3522

I am a student of the North-West University, and I am asking you to help me learn about the food that the people staying at ....(Amelia and Uitkoms) eat. Will you please take time to read through this form that explains everything about the project? You can ask the researcher anything about the project that you do not fully understand. It is important that you know how you can help with the project and that you are happy with everything. You can decide, by yourself, if you want to take part in this project or not. It is your free will to decide. If you do not take part in this project it will not harm you in any way. Even if you say yes to take part, you can stop at any time if you do not want to take part any longer.

The **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00070-16-S1)** has allowed us to do the project. The project is conducted according to very strict guidelines and rules of Ethics in Health Research that was set up by the Department of Health of South Africa and other countries of the world. Members of the Ethics in Health Research may look at the results of this project in the future to see if we followed the strict guidelines and rules.

**What is this project about?**

- This project will be at..... (Amelia/ Uikoms) and will include at least 60 people. If you decide to take part in this study, this is what will happen – we will come to the place where you work and will measure your weight, how tall you are and around your body at the middle and hip. We will write down what you eat and drink at breakfast, lunch, and dinner for three days. We have done this many times before and learned about it at the North West University. Dr Chrisna Botha-Ravyse knows a lot about the exercise that sick and healthy people must do and also about what they must eat. Mrs Sanet Dreyer knows a lot about the food that sick and healthy people must eat.
- In this project we want to learn:
  - what food, drinks, and snacks you eat and drink at (Amelia/ Uikoms);
  - what food, drinks, and snacks you like to eat and drink when you are at (Amelia/ Uikoms);
  - what your weight is, how tall you are and what the distance around your body is; and
  - if the food and drinks you have at (Amelia/Uikoms) have an effect on your weight, and the distance around your body.

**Why have you been asked to take part?**

- You have been asked to take part because you stay at (Amelia/Uikoms) and we would like to know what you eat and drink and have as a snack while you are staying here.
- We asked you to help with this project because you are between 18 and 40 years old and eat at the dining room without help.
- You will not be able to help with this project if you eat other food than the others; if you have any of the following: diabetes, uncontrolled high blood pressure, severe heart disease, cancer, severe depression, autism, and have an eating disorder; or are 40 years and older.
- You will not be able to help with this project if you are not able to speak clearly; are in a wheel chair; or are not able to stand on a scale.
- If you are physically disabled and not intellectually disabled you will not be able to take part in the project.

### **What must you do?**

- When we first visit you we will explain and show you how we will measure your weight, how tall you are and around your body at the middle and hip. Consent forms will be handed out. This is a form where you will say yes, if you want to be part of the project.
- When we visit you again we will get the consent forms from the people that want to take part in the project. We will ask (Amelia/Uitkoms) what your age is, if you are a man or woman, what your disability and illnesses is, if you smoke, drink alcohol, and what medicine you take or anything else that you drink. We will then take your weight, height (how tall you are) and distance around your body at your middle and hip. Someone you know well and that you can choose (parent, care taker) must be with you.
- We will come to visit three more times and will write down everything you have eaten in the morning, afternoon, and evening; and also from the snack shop.

### **What will you gain from taking part in this project?**

- This project will show you if your weight is like it should be or not.
- We will give the care takers and your family healthy food ideas on how to improve your food intake at Amelia/Uitkoms and at home.

### **Do you need to be scared taking part in this project?**

- There is no reason for you to be scared about taking part in this project.
- You do not have to pay any money to take part.
- You will gain more than lose by taking part in this project.

### **What will happen should you feel a bit uncomfortable being part of this project?**

- If you have any questions about this project, you can ask the research team or your care taker.
- If you feel unwell, shy, nervous, scared or upset (at any time during the project), one of your care takers will be there to take you to a comfortable room.
- You can stop taking part in this project at any time.

### **Who will see the information gathered from this project?**

- Only the researchers (it is someone whose job it is to study a subject carefully) and the people working with the numbers will see the information gathered from the project.
- Your name is not written with any information gathered.
- There will only be a number in the place of your name, and only the researcher will know your number.

- If we have all the answers we are looking for, and write it in an article, nobody will know the name of your care centre or your name.
- All the information will be kept for 5 years on a computer and it will be kept secret with a password.

**What will happen with the information gathered?**

The results of this project can appear in a journal where other researchers can read it, or told at a training session for other researchers, but no names of people or care centres who took part in the project will be mentioned.

**Will you be paid to take part in this project and are there any costs involved?**

You will not be paid to take part in the study because the researchers come to your care centre, and it will cost you no money to take part in this study.

**Is there anything else that you should know?**

- You are welcome to ask any questions before you decide to take part in this project. You can call me directly on (082 856 2310) and Dr Chrisna Botha-Ravayse, the project leader (016 910 3522).
- You can also contact the Human Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206; carolien.vanzyl@nwu.ac.za if you have any problems or complaints that have not been listened to or handled by the researcher.
- You will receive a copy of this form to keep for yourself.

**How will you know about the findings?**

The findings will be shared with you at a meeting as soon as it is ready. You are welcome to contact us about the findings of the project.

**Declaration by participant:**

By signing below, I ..... agree to take part in this project  
**Dietary intake practices of intellectual disabled (ID) adults in a controlled care centre environment.**

I declare that:

- My caregiver (parent/guardian/manager of care centre) already gave consent (permission) for me to take part in this project.
- I have read this information/ it was explained to me by a trusted person in a language in which I am fluent and comfortable.
- The project was clearly explained to me.
- I have had a chance to ask questions to both the person obtaining consent (permission), as well as the researcher and I have no more questions about the project.
- I understand that taking part in this project is **voluntary** (out of my own free will) and I have not been forced to take part.
- I may choose to leave the project at any time and it will not harm me in any way.
- I may be asked to leave the project before it has finished, if the researcher feels it is in my best interest, or if I do not follow the project plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

**Signature of participant**

.....

**Signature of witness**

**Declaration by person obtaining consent (permission)**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

**Signature of person obtaining consent**

**Signature of witness**

**Declaration by researcher**

I (*name*) ..... declare that:

- I explained the information in this document to ..... **or** I had it explained by ..... who I trained for this purpose.
- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

**Signature of researcher**

**Signature of witness**

**Informed consent for intellectual disabled adults participating in study (by proxy)**

**Dietary intake practices of adults with intellectual disability in a controlled care centre environment**

**REFERENCE NUMBERS:** NWU-00070-16-S1

**PRINCIPLE INVESTIGATOR:** Dr Chrisna Botha-Ravyse

**STUDENT INVESTIGATOR:** Sanet Dreyer

**ADDRESS:** North-West University, Vaal Triangle Campus

Hendrik van Eck Boulevard

Vanderbijlpark

1911

**CONTACT NUMBER:** (016) 910-3522

I am a student from the North-West University and ask the intellectual disabled (ID) adults living in ..... (Amelia and Uitkoms) to take part in a project to help me learn about the food that they eat and drink at their care centre. Will you please take time to read through this form that explains everything about the project? They can ask the researcher anything about the project that they do not fully understand. It is important that they know how they can help with the project and if they are happy with everything. They can decide by themselves if they want to take part in this project or not. It is their free will to decide. If they do not take part in the project it will not harm them in any way. Even if they say yes to take part, they can stop at any time if they do not want to take part any longer.

The **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00070-16-S1)** has allowed us to do the project. The project is conducted according to very strict guidelines and rules of Ethics in Health Research that was set up by the Department of Health of South Africa and other countries of the world. Members of the Ethics in Health Research may look at the results of this project in the future to see if we followed the strict guidelines and rules.

**What is this project about?**

- This project will be at.....(Amelia/ Uikoms) and will include at least 60 people. If they decide to take part in this project, this is what will happen – we will come to the place where they work and will measure their weight, how tall they are and around their body at the middle and hip. We will write down what they eat and drink at breakfast, lunch, and dinner for three days. We have done this many times before and learned about it at the North West University. Dr Chrisna Botha-Ravyse knows a lot about the exercise that sick and healthy people must do and also about what they must eat. Mrs Sanet Dreyer knows a lot about the food that sick and healthy people must eat.
- In this project we want to learn:
  - what food, drinks, and snacks they eat and drink at (Amelia/ Uikoms)
  - what food, drinks, and snacks they like to eat and drink when they are at (Amelia/ Uikoms)
  - what their weight, how tall they are and the distance around their body (at the middle and hips) are; and
  - if the food, drinks and snacks they have at (Amelia/Uikoms) have an effect on their weight and the distance around their body.

**Why have residents of Amelia/ Uikoms been asked to take part?**

- They have been asked to take part because they stay at Amelia/Uikoms and we would like to know what they eat and drink and have as a snack while they are staying there.
- We asked them to help with this project because they are between 18 and 40 years old and can eat at the dining room without the help of a care taker.
- They will not be able to take part in the project if they have any of the following: diabetes, uncontrolled high blood pressure, severe heart disease, cancer, severe depression, autism, and an eating disorder, or are 40 years old and older.
- They will not be able to help with this project if they are not able to speak clearly; are in a wheel chair, or are not able to stand on a scale.
- Adults that are physically disabled but not intellectually disabled will not be able to take part in this project.

**What must they do?**

- When we first visit them we will explain to and show them how we will take their weight, height (how tall they are) and distance around their body. Consent (permission) forms will be handed out. This is a form where they will say yes, if they want to be part of the project. One of the staff members will be responsible for assisting them and collecting the forms.

## ANNEXURE A: ASSENT AND CONSENT FORMS

- When we visit again, we will get the consent forms of all the people who want to take part in the project, from the responsible staff member. We will ask residents at (Amelia/Uitkoms) what their age is, if they are a man or woman, and what their disability and illnesses is, if they smoke and/or drink alcohol, and what medicine they take. We will then take their weight, height (how tall they are) and distance around their body (at the middle and hips). Someone they know well and that they can choose (parent, care taker) must be with them.
- We will come to visit three times more and will write down everything they eat in the morning, afternoon, and evening and also from the snack shop.

### **What will he/she gain from taking part in this project?**

- This project will show them if their weight is like it should be or not.
- We will give the care takers and the family of the people living at Amelia/Uitkoms healthy food ideas on how to improve their food intake at Amelia/Uitkoms and home.

### **Do the people taking part in the project need to be scared?**

- There is no reason for them to be scared when taking part in this project.
- They do not pay any money to take part in the project.
- They will gain more than lose if they take part in this project.

### **What will happen should they feel a bit uncomfortable being part of this project?**

- If they have any questions about the project, they can ask us (the research team) or their care taker.
- If they feel unwell, shy, anxious, scared or upset (at any time during the project), one of the care takers will be there to take them to a room to comfort them.
- They can stop taking part in this project at any time.

### **Who will see the information gathered from this project?**

- Only the researchers (it is someone whose job it is to study a subject carefully) and the people working with the numbers will see all the information gathered from this project.
- The names of the people and care centres taking part in the project will not be written with the results of the project.
- There will only be a number in the place of participants' names, and only the researcher will know the number.
- If we have all the answers we are looking for, and write it in an article, nobody will know the name(s) of the care centre or the people that took part in the project.

- All the information will be kept for 5 years on a computer and it will be kept secret with a password.

**What will happen with the information gathered?**

- The results of this project can appear in a journal where other researchers can read it, or told at a training session to other researchers, but no names of people or care centres who took part in the project will be mentioned.

**Will the people taking part in the project receive any money?**

They will not receive money to take part in the project because the researchers come to the care centre. It will cost them no money to take part in the project.

**Is there anything else that you should know?**

- They are welcome to ask any questions before they decide to take part in this project. They can call me directly on (082 856 2310) and Dr Chrisna Botha-Ravyse, the project leader (016 910 3522).
- They can also contact the Human Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206; carolien.vanzyl@nwu.ac.za if they have any problems or complaints that have not been listened to or handled by the researcher.
- They will receive a copy of this form to keep for themselves.

**How will you know about the findings?**

The findings of the project will be shared in a planned meeting with everyone who was part of the project. They are welcome to contact us about the findings of the research.

**Declaration by proxy (legal guardian/ parent):**

By signing below, I ..... (full names and surname) give consent for ..... (full names and surname) to take part in a research study **Dietary intake practices of intellectual disabled (ID) adults in a controlled care centre environment.**

I declare that:

- I have read this information/ it was explained to me by a trusted person in a language in which I am fluent and comfortable.
- The project was clearly explained to me.

ANNEXURE A: ASSENT AND CONSENT FORMS

- I have had a chance to ask questions to both the person obtaining consent (permission), as well as the researcher and all my questions have been adequately answered.
- I understand that the ID participants take part in this study on a **voluntary** basis and that the ID participant has not been pressurised to take part.
- The ID participant may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- The ID participant may be asked to leave the study before it has finished, if the researcher feels it is in his/her best interests, or if he/she does not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

**Signature of guardian or parent**

**Signature of witness**

**Declaration by person obtaining consent (permission)**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

**Signature of person obtaining consent (permission)**

**Signature of witness**

**Declaration by researcher**

I (*name*) ..... declare that:

ANNEXURE A: ASSENT AND CONSENT FORMS

- I explained the information in this document to ..... **or** I had it explained by ..... who I trained for this purpose.
- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

**Signature of researcher**

.....

**Signature of witness**

**Informed consent form staff participating in focus group discussions**

**Dietary intake practices of adults with intellectual disability in a controlled care centre environment**

**REFERENCE NUMBERS:** NWU-00070-16-S1

**PRINCIPLE INVESTIGATOR:** Dr Chrisna Botha-Ravyse

**STUDENT INVESTIGATOR:** Sanet Dreyer

**ADDRESS:** North-West University, Vaal Triangle Campus

Hendrik van Eck Boulevard

Vanderbijlpark

1911

**CONTACT NUMBER:** (016) 910-3522

I am a student from the North-West university, and I am asking you to help me to learn about the food that the people staying at .... (Amelia and Uitkoms) eat. Will you please take time to read through this form that explains everything about the project? You can ask the researcher anything about the project that you do not fully understand. It is very important that you know how you can help with the project and that you are happy with everything. You can decide by yourself if you want to take part in this project or not everything, and that you know how you can help with the project, and that you are happy with everything. You can decide on your own to take part or not to take part in the project. It is your free will to decide. If you do not take part in this project it will not harm you in any way. Even if you say yes to take part, you can stop at any time if you do not want to take part any longer.

The **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU-00070-16-S1)** has allowed us to do the project. The project is conducted according to very strict guidelines and rules of Ethics in Health Research that was set up by the Department of Health of South Africa and other countries of the world. Members of the Ethics in Health Research may look at the results of this project in the future to see if we followed the strict guidelines and rules.

**What is the research study about?**

- This project will be at.....(Amelia/ Uikoms) and will include all staff that work closely with the people living at the centre that are intellectually disabled. If you decide to be part of this project, this is what will happen – we will come to the care centre about six times; we will talk to you in small groups of seven to eight staff members about the food the people living at Uikoms/Amelia eat during the day and night and the snacks they have. Each group discussion will last 45 to 60 minutes. The discussion will be in English, but you can ask for an Afrikaans translation at any time during the discussion and are allowed to answer in Afrikaans.
- Dr Chrisna Botha-Ravyse will lead the groups. She has been formally trained to do these talks in small groups. She has done this many times in the past.
- In this project we want to learn:
  - what food, drinks, and snacks residents eat and drink at (Amelia/ Uikoms);
  - what food, drinks, and snacks residents like to eat and drink at (Amelia/ Uikoms);
  - what residents' weight, height and the distance around their body are; and
  - if the food and drinks residents have at (Amelia/Uikoms) have an effect on their weight, height (how tall you are) and the distance around their body.

**Why have you been asked to take part?**

- You have been asked to take part because you are a care taker and know the people living at Amelia/Uikoms well and will be able to give us more information on what they like to eat and drink, and what food and drinks they have in-between meals.

**What must you do?**

- On our first visit, we will give you more information on the small group talks. You will have ample time to ask questions about your role in the project. Consent (permission) forms will be handed out.
- On the second visit, we will collect the consent (permission) forms from those wishing to take part in the project.
- The date for the focus group discussions will be arranged 4 weeks in advance with the manager of the care centre so that you will be able to take part in the group talks, without your work being compromised (affected). We will record and write down

everything said during the discussions. It will take place in a quiet, private, and comfortable room. There will be enough water to drink.

- It is important that you will answer all the questions in the group talks honestly; telling us what you think. There is no right or wrong answer. It is important not to tell anyone afterwards what we talked about.

**Will you gain from taking part in this project?**

- With all the information gathered by the researchers, we will be able to help and guide the care centre on planning the menu and improve the eating, drinking, and snacking habits of the people living at Amelia/ Uitkoms.

**Are there risks involved in you taking part in this project?**

- There are no risks for you when taking part in the project.
- It will cost you nothing to take part.
- Even though we will ask the group members not to talk about what we talked about in the group talks, they can still do that without us knowing it.
- You will gain more than lose if you take part in this project.

**What will happen should you feel a bit uncomfortable because you are taking part in this project?**

- If you have any questions about this project, you can ask us or your manager.
- You can stop taking part in this study at any time you want to.

**Who will see the information gathered from this project?**

- Only the researchers and the person working with the numbers will see the comments made during the group talks.
- Your name is not written with any information gathered.
- There will only be a number in the place of your name, and only the researcher will know your number.
- If we have all the answers we are looking for, and write it in an article, nobody will know the name of your care centre or your name.
- All the information will be kept for 5 years on a computer and it will be kept secret with a password.
- All recordings of the discussions will be destroyed as soon as the researchers have worked through it.
- All documents of the findings will be in locked in cupboards in the researcher's office. All the information on computers will be kept secret with a password for 5 years.

**What will happen with the information gathered?**

The results of this project can appear in a journal where other researchers can read it, or told at a training session to other researchers, but no names of people or care centres who took part in the project will be mentioned.

**Will you be paid to take part in this study and are there any costs involved?**

This study will be funded by Dr C.R. Botha-Ravyse and the Centre of Excellence for Nutrition at the North-West University. You will not be paid to take part in the study because the researchers come to your care centre, and it will cost you no money to take part in this project. Water and/or refreshments will be available.

**Is there anything else that you should know?**

- You are welcome to ask any questions before you decide to give consent. You can call me directly on (082 856 2310) and Dr Chrisna Botha-Ravyse, the project leader (016 910 3522).
- You can also contact the Human Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206; carolien.vanzyl@nwu.ac.za if you have any problems or complaints that have not been listened to or handled by the researcher.
- You will receive a copy of this information and consent form for your own records.

**How will you know about the findings?**

The findings will be shared with you at a meeting as soon as it is ready. You are welcome to contact us about the findings of the project.

**Declaration by participant:**

By signing below, I ..... agree to take part in this project  
**Dietary intake practices of intellectual disabled (ID) adults in a controlled care centre environment.**

I declare that:

- I have read this information and consent form and it is written in a language in which I am fluent and comfortable.
- I have had a chance to ask questions to both the person obtaining consent (permission), as well as the researcher and all my questions have been adequately answered.
- I understand that taking part in this project is **voluntary** (out of my own free will) and I have not been forced to take part.

ANNEXURE A: ASSENT AND CONSENT FORMS

- I may choose to leave the project at any time and it will not harm me in any way.
- I may be asked to leave the project before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

Signature of participant

Signature of witness

**Declaration by person obtaining consent**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 20....

.....

.....

**Signature of person obtaining consent**

**Signature of witness**

Declaration by researcher

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

## **ANNEXURE B: INTERVIEW SCHEDULE**

1. What is the meal times and in-between snacking times during the week (and weekends)?
2. Does the menu during the week differ from the menu at weekends?
3. Tell us more about how you celebrate birthdays. What happens during other special occasions, for example, year-end parties?
4. Let's talk about other snacking times at the centre (for example, after dinner, late afternoon).
5. Tell us more about the snack shop. How does it work? Where do they get the money? What do they prefer to buy? What are the popular snacks?
6. What happens to those who are overweight, have diabetes, and are struggling with high blood pressure and cholesterol? Are there special diets for them?
7. Do you receive donations from, for example, farmers? What do you do with the donations? How often do you receive donations?
8. Tell us more about the availability of drinking water at the centre.
9. What control measures regarding food portions do you have at the centre? Are there any other control measures?
10. Is there anything you would like to see change about the residents' food or "snacks" or even their menu? Why? Any suggestions?
11. What are their favourite dishes on the menu?
12. Until what time is the caregiver on duty at night? What happens after that regarding snacking?
13. Tell us more about food that are kept in their rooms. Do they bring food from home?

## ANNEXURE C: CERTIFICATE OF EDITING

☎016-9103512

📞0730747520

✉natasha.ravyse@nwu.ac.za

**Natasha Ravyse**

LANGUAGE PRACTITIONER

Member: Professional Editors' Guild (mentor)

Member: South African Translators' Institute

### EDITING CERTIFICATE

Mrs S. Dreyer

29.11.2017

This certificate serves to confirm that the MA Dissertation with the title, *Dietary practices of intellectually disabled adults in a controlled care centre environment*, has undergone a professional language and reference edit. It is important to note that all content in the thesis, including argumentation, remains the responsibility of the client and the supervisor. The onus rests on the client to work through the proposed changes after the edit has been completed, and either accept or reject the proposed changes.



Natasha Ravyse

## ANNEXURE D: AUTHORS' GUIDELINES

### 1. Manuscript Submission

*American Journal on Intellectual and Developmental Disability* (AJIDD) uses a Web-based manuscript submission and peer-review system called AllenTrack. Manuscripts should be submitted electronically to [ajidd.allentrack.net](http://ajidd.allentrack.net). Given that all manuscripts will be reviewed anonymously, the author's name and other identifying information should appear only on the cover page. Potentially identifying information in the text should be removed prior to submission. The journal's Editor and Associate Editors oversee manuscript reviews. Once a manuscript is submitted, an Editor-in-Charge is assigned who is responsible for assigning the peer reviewers and deciding on the disposition of all manuscripts (acceptance, rejection, or requests for revision). The initial review process ordinarily takes from 8 to 10 weeks, and revisions are often requested. Once a manuscript is accepted for publication, the remainder of the production process is coordinated by AAIDD's Publications Department ([journals@aaidd.org](mailto:journals@aaidd.org)).

Corresponding authors who require assistance in submitting their manuscripts through AllenTrack should contact the editorial office via e-mail at [Deborah.Fidler@ColoState.edu](mailto:Deborah.Fidler@ColoState.edu). AllenTrack can convert most word-processing files (e.g., Word, WordPerfect, Text, Postscript, and Rich Text Format).

### 2. Before submitting a manuscript, please gather the following information:

All Authors

First Names, Middle Names/Initials, Last Names

Institution

Department

E-mail addresses

Title and Running Title (you may copy and paste these from your manuscript)

Abstract (you may copy and paste this from your manuscript)

Key words

Manuscript files in Word (doc), WordPerfect (wpd), or Rich Text Format (rtf)

All tables and figures will have to be provided as either Word or Excel files.

The separate **Cover Page**, Word (doc), WordPerfect (wpd), or Rich Text Format (rtf) should include the following elements:

### 3. CoverPage

TITLE OF MANUSCRIPT (*All Authors First Names, Middle Initials [if applicable], Surnames [in order of authorship]*)

Corresponding Author: **Author Name** Highest degree earned, title (if applicable) Email address:  
xxxx@xxx.edu

Institutional Affiliation Departmental Affiliation Street Address City, State, Zip, Country

**Second Author Name** Highest degree earned, title (if applicable), affiliation, city, state, zip,  
country

**Third Author Name** Highest degree earned, title (if applicable), affiliation, city, state, zip,  
country

**\*Please provide information for all authors**

#### 4. **Acknowledgments**

Where was manuscript presented, oral or poster? Was this manuscript funded? By what entity? Grant number(s), if applicable. Thanks for support, if desired

Manuscript files [(Word (doc), WordPerfect (wpd), or Rich Text Format (rtf)] should not contain any identifying information, but should include the following:

Title

Abstract

Key words

Manuscript Text

#### 5. **Ethical Standards**

The human subjects review committee of the author's institution must have approved all investigations using human participants. Submission of a manuscript to *AJIDD* while that paper is under review by another journal is unacceptable. Presentation of a manuscript in electronic form on the Internet is considered to constitute publication and may be grounds for rejection of the paper by this journal.

#### 6. **Form**

Manuscripts should be prepared in accordance with the 2009 *Publication Manual of the American Psychological Association* (APA, 6th edition). All sections of the manuscript (including quotations, references, and tables) should be double-spaced with a 1-inch margin on all sides. References must be in APA style. An abstract of no more than 120 words is required. The preferred length of manuscripts is 20–30 typed pages or less, including references, but somewhat greater length may be accepted, depending on the complexity and importance of the research. Brief reports are generally 5–10 manuscript pages and contain a limited number of findings in comparison to research articles. Authors are encouraged to submit shorter, more concise manuscripts.

Any accompanying figures must be submitted as separate files (not embedded in the text) and must be over 200 dpi resolution. It is the authors' responsibility to submit publishable graphic elements. Any graphics that are of a lower resolution than 200 dpi will be rejected. Usually, figures submitted directly from a software application such as Excel are too low quality.

## 7. Abbreviations and Terminology

Abbreviations should be held to a minimum and spelled out in their first use. The names of groups or experimental conditions are usually not abbreviated. The full names of tests should be given when they are first mentioned, with the common shortened form in parentheses with a citation of the source.

When context makes it clear whether an author is referring to people with intellectual disabilities or when it is otherwise unnecessary to refer to intellectual level or diagnostic category, authors should use the most descriptive generic terms, such as children, students, or people or individuals (not persons), without using qualifiers such as "with intellectual disabilities," "with handicaps," or "with developmental disabilities." The journal adheres to AAIDD's use of people-first language. Prepositional constructions such as "students with intellectual disabilities" or "individuals who have intellectual disabilities" are preferred over adjectival constructions such as "intellectual disabilities people," except when clear communication dictates occasional use of adjectival designations. Because "normal" has multiple meanings and may inappropriately imply abnormal where it is not applied, this word should not be used. Instead, more operationally descriptive terms such as *intellectually* average pupils or *typical* participants should be used.

## 8. Numerical and Illustrative Presentations

The metric system should be used for all expressions of linear measures, weight, and volume. Any accompanying figures must be submitted as separate files (not embedded in the text). Please note that any tables or figures accompanying your article will reproduce in black and white. All figures must be high-resolution images, scanned at an absolute minimum of 200 dpi (dots per inch); please ensure this benchmark when resubmitting your article. Submission of figures of insufficient visual quality may delay publication of your article. It is the authors' responsibility to submit figures of an appropriate quality. Submission of figures of insufficient visual quality may delay publication of your article. Release forms (signed, dated, and witnessed) must accompany photographs of human subjects. Care should be taken to conceal the identity of persons in such photographs. Authors must also secure permission to use any copyrighted tables or figures. For tips on ensuring your figure is at an acceptable quality, please visit [http://allenpress.com/system/files/pdfs/library/apmk\\_digital\\_art.pdf](http://allenpress.com/system/files/pdfs/library/apmk_digital_art.pdf).

## 9. Footnotes

Content footnotes are not used. An author note can be used to (a) acknowledge grant support or help in carrying out the research or in preparation of the manuscript, (b) noting change in affiliation of an author, or (c) stating the availability of supplementary information.

## 10. Data-Sharing

After research results are published, authors do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive

claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release. For further information, check our Web site: [www.aaid.org](http://www.aaid.org).

**11. Copyright Assignment**

In view of the U.S. Copyright Revision Act of 1976, if a manuscript is accepted for publication, authors are asked to sign a Copyright Assignment and Agreement form conveying all copyright ownership to AAIDD. For papers funded through grants from the National Institutes of Health and/or The Wellcome Trust, authors are permitted to submit their final, accepted paper to the respective public database, following the terms set forth in the copyright assignment form signed by all authors whose work is accepted for publication.

The points of view expressed in AJIDD's articles are those of the authors and do not necessarily represent the official policy or opinion of AAIDD.

**12. Copyright Clearance Center**

The American Association on Intellectual and Developmental Disabilities has registered its journals and books with the Copyright Clearance Center (CCC). For permission to photocopy articles or other material, please contact Customer Relations, CCC, 222 Rosewood Dr., Danvers, NJ 01923, or phone 978-750-8400, fax 978-646-8600, e-mail [info@copyright.com](mailto:info@copyright.com), or visit [www.copyright.com](http://www.copyright.com).

**13. Staff**

Editor: Deborah Fidler, Colorado State University

**14. Editorial Office Address**

Deborah Fidler, PhD, Colorado State University, 313 Behavioral Sciences Building, Fort Collins, CO 80523-1570

<http://aaidjournals.org/page/authors/ajidd?code=aamr-site>

**ANNEXURE E: PROOF OF SUBMISSION OF ARTICLE.****Detailed Status Information**

<b>Manuscript #</b>	17-614
<b>Current Revision #</b>	0
<b>Submission Date</b>	2017-11-29
<b>Current Stage</b>	Initial QC Started
<b>Title</b>	Dietary intake practices of adults with intellectual disability in a controlled care centre environment
<b>Running Title</b>	Diet of intellectual disabled adults
<b>Manuscript Type</b>	Research Article
<b>Special Issue</b>	N/A
<b>Corresponding Author</b>	Chrisna Botha-Ravuse (North-West University, Potchefstroom, South Africa)
<b>Contributing Authors</b>	Sanet Dreyer , Susanna Hanekom
<b>Financial Disclosure</b>	I certify that all financial and material support for this research and work are clearly identified in the manuscript. Details regarding this support have been fully outlined in my cover letter.
<b>Abstract</b>	Background: High obesity prevalence among adults with intellectual disability (AWID), increases their risk for non-communicable diseases. The aim of this study was to assess the dietary intake practices of AWID in a controlled, care centre environment. Methods: A mixed-methods design, was followed. Demographic data, along with a three-day plate waste study was collected from 66 AWID. Focus group discussions were held with staff members to obtain more information on the dietary practices of the AWID. Results: The quality of the dietary intake was low. Caregivers expressed a need for cooking skills training, menu variety and, healthier snacks. Conclusions: The dietary intake in this study population needs improvement. Training in recommended and should be accompanied by professional dietetic input.
<b>Associate Editor</b>	Not Assigned
<b>Key Words</b>	intellectual disability, dietary practices, dietary intake, dietary quality