Health promotion for people with intellectual disability and obesity

Catriona M Doody and Owen Doody

Abstract
Obesity is a significant health problem for people with intellectual disability, as they report a 59% higher rate of obesity as compared with those in the general population (Centres for Disease Control and Prevention, 2006). Causes are multifactorial and obesity leads to a higher risk of developing chronic conditions, such as diabetes and heart disease. While the risks of these conditions generally increase with age, people with an intellectual disability are at risk of developing them earlier owing to their higher levels of obesity. Client groups with mild intellectual disability residing in a group home or family home are at a higher risk of obesity than those in institutional care, mainly owing to increased independence and available choices. Healthcare services have predominantly focused on the primary disability rather than on prevention or reduction of secondary health conditions. As health promotion enables people to gain control over their lives, it is essential to address the health concern of obesity for people with intellectual disability. This article highlights the issues in health care faced by people with an intellectual disability and aspects that health professionals need to consider when engaging in health promotion for those who are obese.

Key words: Obesity, health promotion, Intellectual disability, Management, Evaluation

Introduction
Obesity is a significant health problem within the intellectual disability population (Blair and Nichaman, 2002), as a higher proportion are overweight or obese compared with the general population (Marshall et al, 2003; Draheim, 2006). The Centres for Disease Control and Prevention (CDC) reports this rate is higher by 59% (CDC, 2006). Causes are multifactorial and include poor eating behaviours, high inappropriate caloric eating, depressed metabolic rate, reduced exercise, hypotonia and endocrine abnormalities (Mokdad et al, 2004; Fisher and Ketti, 2005). Obesity presents a higher risk of developing many chronic conditions, such as hypertension, diabetes, heart disease, arthritis, stroke, stress, depression, respiratory diseases and even sleep disorders (Ells et al, 2006; Haveman et al, 2010). Additionally, although the risks of these conditions increase with age, young adults with intellectual disability are at risk of developing them earlier because of their high levels of obesity (Janiciki et al, 2002). Client groups with a mild intellectual disability that reside in either a group home or family home setting are at a higher risk of obesity and excess body weight than those in institutional care (Melville et al, 2005; Draheim, 2006). The notion of supported living and assisted independent living has been promoted as people gain more independence and responsibility (McNally, 2006; Hart, 2007). However, less restrictive living environments may be associated with reduced supervision and increased promotion of individual choice, which may result in greater access to fast food and less emphasis on physical activity (Draheim, 2006; Johnson, 2009). Possible explanations for this include that individuals with intellectual disability may be less conscious of health risks associated with excessive body weight (Bodde and Seo, 2009); they may not be given adequate opportunities to gain knowledge of health risks as part of their experiences in community services (Jobling,
Obesity has both societal and personal costs, having the potential to reduce or limit opportunities for community participation, employment and leisure, while also requiring greater effort from the carer in assisting with activities of daily living (Lin et al., 2005). This necessitates implementing interventions and supportive strategies to reduce and protect this group from the adverse health effects of excess weight and body fat (Moore et al., 2004). Health promotion aims to enable people to gain control over their lives (World Health Organization (WHO), 1986) and refers to health in a broad sense including physical, mental and social health (Ewles and Simnett, 2010) focusing on primary, secondary and tertiary prevention (Hart, 2007). Within intellectual disability, the emphasis in health care has predominantly been directed at the primary disability rather than on prevention or reducing secondary health conditions (Marshall et al., 2003). This emphasis on prevention or management of disability may indicate a possible reason why health promotion issues have not been addressed for people with an intellectual disability (Rimmer, 2002), and terms such as ‘wellness’ and ‘health promotion’ are not often associated with this population (Rimmer, 1999; Marshall et al., 2003). Public health and health promotion are common approaches to lifestyle change for the general population; however, these interventions are often not effective for people with intellectual disability (Rimmer, 2002). As a result, people with an intellectual disability need greater support in attempting to improve their health (van Hooren et al., 2002), and health promotion needs to be delivered in a format that is accessible for them (Fraser and Fraser, 2001). This may be achieved if health promotion initiatives contain information relevant to people with intellectual disability and is provided in a clear language that is easily understood. However, physical, attitudinal and knowledge barriers limit participation, making it difficult for people with intellectual disability to engage in health promotion behaviours, and lead to social exclusion (Spitalink and White-Scott, 2001).

Traditionally, health promotion through healthy eating only commenced when obesity became a recognisable problem for people with intellectual disability. By this time, however, eating patterns that have led to obesity are well established and re-education is more difficult (Jobling, 2001). Health promotion needs to direct its strategies of health gain, health surveillance, health awareness and healthy lifestyle encouragement toward people with intellectual disability (Hart, 2007), enabling people with intellectual disability to remain healthy and in the event of ill health, access and receive the best possible health care (Hart, 2007). Planning is essential for resources to be directed where they will have the most impact, ensuring health promotion is not overlooked but prioritised as a work activity (Naidoo and Wills, 2009). Such planning needs to address the components of health promotion (Box 1) and incorporate education, behaviour, empowerment and social change issues (Ewles and Simnett, 2010). This article highlights the issues within health care encountered by people with intellectual disability and methods to support health professionals who are working to promote health for those with intellectual disability who are obese.

<table>
<thead>
<tr>
<th>Box 1. Four components of health promotion for people with intellectual disability</th>
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<tr>
<td>• The promotion of healthy lifestyles and a healthy environment</td>
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<tr>
<td>• The prevention of health complications and further disabling conditions</td>
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<td>• The preparation of the person with a disability to understand and monitor his</td>
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or her own healthcare needs

- The promotion of opportunities for participation in commonly held life activities

*Source: Adapted from US Department of Health and Human Services and Public Health Service, 1998*

**Intellectual disability and health care**

Primary care is the focus of care provision for 90-95% for all health needs (Doody et al, 2011). Therefore, there is an increased likelihood that health professionals within the primary care system will encounter people with intellectual disability who are obese. This often presents a double disadvantage as health professionals are often ill-equipped to deal with this combination. It is acknowledged that health professionals’ attitudes can have a significant impact on their interaction with people with intellectual disability (Iacono and Davis, 2003). This attitude often stems from the traditional view of intellectual disability as a personal tragedy and one that requires solutions through medical intervention. However, these attitudes fail to recognise the social nature of intellectual disability and provide support to remedy the environment that is at the basis of many problems. Additionally, it is acknowledged that there is a low uptake of services by people with intellectual disability owing to barriers, such as language and communication difficulties (Iacono and Davis, 2003), lack of accessible information (Cumella and Martin, 2004), negative past experiences (Brown and Guvenir, 2009) and the experience of significant stress caused by health professionals’ limited knowledge or understanding of intellectual disability (Webber et al, 2010). A lack of competence on the part of the health professional may inadvertently indicate a lack of understanding, discrimination or value judgment regarding the worth of people with intellectual disability (Mencap, 2004). Perceived negative attitudes towards disability may thus reinforce low uptake of services. However, this does not excuse service providers of the responsibility to address such attitudes and provide information about the supports and resources available.

Often, service users feel that mainstream services are inappropriate for their needs with health professionals seemingly making assumptions based on stereotype or prejudice about what their needs are (Brown and Guvenir, 2009). A ‘colour-blind’ approach, where everyone is treated the same, is often operated within the healthcare system. As a result, the label of intellectual disability may mask other health issues as there is a perception that everyone with an intellectual disability has the same set of needs (McNally, 2007). This attitude tends to disguise the fact that the needs of people with intellectual disability have either not been considered or are being ignored and as such, there is a need for appropriate and targeted information about what services are available for users and potential users (Cumella and Martin, 2004). Valuing People (Department of Health (DH), 2001) has made suggestions for service provision as identified in Box 2.

**Box 2. Suggestions for service provision**

- Better training in intellectual disability for all healthcare staff
- Longer and more flexible appointments
- Accessible information to be provided in all healthcare settings
- All screening programmes to ensure that people with an intellectual disability have the same access rate as others
- Identification on health records that someone has an intellectual disability
- Tackle health inequalities by ensuring a Health Equity Audit to address how
well people with an intellectual disability are accessing mainstream services and propose action to reduce the gap in life expectancy

• Annual health checks should be offered to all people with an intellectual disability
• Hospitals to fulfil their legal duty of care and provide appropriate levels of support to clients with an intellectual disability
• An inquiry into premature deaths should be conducted

Source: Department of Health, 2001

As clients’ and their families’ experiences with health professionals and services are compounded by a lack of information about the facilities and opportunities that are available to people with intellectual disability, they tend to reinforce the notion that individuals with impairments are a ‘burden’ (Gururaj et al, 2008). Therefore, working with intellectual disability clients must include efforts to work in partnership with them and their families from their point of view. Health professionals need to be prepared to fulfil their roles competently in relation to practice and care provision, service provision and education (McNally, 2007).

While Ireland and the UK have specifically trained nurses in intellectual disability, these nurses need to assume a supporting role for other health professionals within their service and across all healthcare settings in order to provide effective services to people with intellectual disability owing to the potential barriers (Doody et al, 2011) (outlined in Table 1) and given that they are the only professional group who are specifically trained to meet the needs of those with intellectual disability (Horan, 2006; Sweeney and Mitchell, 2009). Although, they must first address the issue of how they support people with intellectual disability who are obese within their own services and produce evidence through research, rather than relying on practice wisdom, where the nurse solely operates from their own practice knowledge (Doody and Doody, 2011).

<table>
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<th>Table 1. Potential barriers in primary care</th>
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<td>Healthcare-worker-focused barriers</td>
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<td>Inexperience in working with people with intellectual disability</td>
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<td>Lack of ability to communicate</td>
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<td>Lack of confidence</td>
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<td>Fear of intellectual disability</td>
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<td>Negative assumptions about person’s ability to maintain health</td>
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<td>Inappropriate stereotypes</td>
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![Annoyance](attachment://annoyance.png)

![Frustration](attachment://frustration.png)

Source: Doody et al. 2011

Supporting strategies
Health promotion is a ‘process’ indicating a means to an end and not merely an outcome, it is not something that is done ‘on’ or ‘to’ people, as individuals or groups (Nutbeam, 1998). The principles of client participation and partnership are central to health promotion and involve a voluntary agreement between client, family and health
professional to work towards a set of shared goals (Gillies, 1998). This team-based approach provides opportunities for collaboration and facilitates the development of an understanding of appropriate actions (Hamilton et al, 2007) through facilitating clients, families and health professionals, identifying their health concerns and areas for change (Naidoo and Wills, 2009), and adapting an approach based on their needs. This is essential for effectiveness in promoting, encouraging and supporting weight loss and increased physical activity (Hamilton et al, 2007). As health is a subjective concept influenced by a range of factors, liaison and open communication develops an empowerment approach enabling individuals to meet their own identified problems and mobilise the necessary resources to feel in control (Naidoo and Wills, 2009). Through participation, empowerment is achieved ensuring individuals are involved in decisions that affect their lives and facilitating a client-centred approach (Barr, 2007). This involvement should occur at all stages; assessing, planning, implementation and evaluation of health promotion programmes (Whitehead, 2004; Barr, 2007). Approaches are generally based on education, behaviour or social change and focused on client need. However, the health professional also needs to consider the client’s level of ability and understanding, being careful not to assume that a standard approach will be appropriate for a person with an intellectual disability.

**Educational change approach**

Educational change approach consists primarily of the creation of opportunities for learning to improve one’s personal health (Naidoo and Wills, 2009). Generally, nutrition and diet information is directed towards the general public. However, clients with an intellectual disability need information and knowledge about what is good nutrition and what is a balanced diet, addressing issues such as food selection and food groups (Illingworth et al, 2003). Nutritional programmes need to consider client preferences and their living environment as a plan that fails to consider these will not meet their needs, even if it is nutritionally sound. Health professionals need to provide information on food preparation, food choices, food labels and new ways to alter eating habits in order to enable informed choices regarding behaviour (Naidoo and Wills, 2009). Clients who live independently require education regarding cooking and shopping, focusing on not only the preparation of convenient and easy food, but also the development of an understanding about which foods to select, as well as their importance in contributing to health. The ability to choose and plan healthy and interesting meals of high nutritional value is an essential skill for independent living (Jobling, 2001). Many people with intellectual disability do not meet a balanced diet and experience consistent nutritional impairment (Hamilton et al, 2007). Although knowledge alone is not sufficient for effective change, it is a prerequisite for behavioural change (Illingworth et al, 2003). Therefore, information and education about the relationship between energy intake and energy expenditure should be incorporated into a programme (Illingworth et al, 2003). Promoting appropriate levels of physical activity remains an important component for weight management and should have its place as a long-term life change (Hamilton et al, 2007).

**Behavioural change approach**

Behavioural change promotes health as a result of healthy behaviours and lifestyle (Naidoo and Wills, 2009). The health professional should emphasise the importance of an appropriate sleeping pattern, as those who sleep less than 7 hours a night are more likely to be obese (Patel et al, 2006; Watanabe et al, 2010). Additionally, fatigue produced by limited sleep may reduce physical activity and energy expenditure,
predisposing people to weight gain (Patel et al, 2006). The importance of healthy eating, meal provision, snacking, and fruit and water intake should also be reinforced (Jobling, 2001). Exercise programmes should be designed to complement the practical aspects of everyday life, such as walking, stair climbing, gardening and housekeeping that maintain overall conditioning and flexibility (Jobling, 2001). Activities that combine both exercise and social benefits, such as bowling, dancing and cycling, should be promoted and incorporated into any health promotion initiative in order to support inclusion often as there is an increased social prejudice and non-acceptance within society owing to the social stigmas associated with both having an intellectual disability and obesity (Jobling, 2001; Illingworth et al, 2003). Where possible, activities should be community based and sessions should be conducted in the gymnasium or swimming pool, incorporating movement and stretching while ensuring clients are exercising within their comfort zone and are not exacerbating any other existing conditions (Rimmer, 2005).

**Social change approach**

Social change tackles the underlying causes of ill health, focusing efforts on achieving change in physical, social and economic environments (Naidoo and Wills, 2009). Social variables, such as access to friendships and recreational opportunities, are seen as important predictors of BMI scores in people with intellectual disability, along with diet and other physical status variables (Fujiura and Yamaki, 1997). Therefore, group support is important during any programme to allow individuals to relate to each other and serve as a support mechanism during and after the programme (Rimmer, 1999). Coping strategies are a vital part of health behaviour and poor mental health status could undermine the success of the programme (Jobling, 2001). Therefore, participants should be supported to develop new ways of coping with stressful events or situations. Holism is central to complementary therapies and the care of people on a physical, psychosocial and spiritual level (Long et al, 2000). Therefore, relaxation methods, deep breathing exercises and aromatherapy could be incorporated. To grow as individuals, we acquire knowledge. However, often the trick is finding people who have the information and by bringing people together, knowledge and resources can be shared and generated (Goldman and Schmalz, 2001). For change to be effective, it has to be based on the individual’s identified need and a specific programme must be tailored to meet those needs.

The negative impact of obesity on health is a priority (Melville et al, 2005), indicating the necessity to implement health promotion sessions where the importance of exercise and diet are promoted in a way that is meaningful and enjoyable for the client (Moore et al, 2004). It is essential to keep messages clear and simple; addressing the aspects of the health promotion programme individually is more effective in creating understanding and modifying lifestyles than transmitting a number of interrelated messages (Hart, 2007). Giving up existing behaviours may unintentionally imply that adopting a healthier lifestyle is to adopt an undesired lifestyle (Hart, 2007). Therefore, extreme care must be taken to ensure that health promotion messages are understood as positive life changes (Hart, 2007). Consequently, to support and include people with intellectual disability within the health promotion programme, their existing knowledge of how to maintain health needs to be identified and assessed (Fraser and Fraser, 2001). This can be achieved using the Nutritional and Activity Knowledge Scale (NAKS) designed by Illingworth et al (2003), which identifies clients’ knowledge and understanding of foods and nutrition.
People with intellectual disability are often disabled in their own emotional and intellectual creativity as a result of low expectations and judgements of those around them (Wilberforce, 2007). Engaging in brainstorming exercises will focus on the generation of ideas about their life without judgement, where what is interesting is more highly valued than what is correct. Encouraging each person to generate an idea develops a collaborative process and group work can set the stage for prioritising ideas (Hafler, 2003), as well as create a starting point for an intervention programme. In order to develop an intervention programme, the setting should be considered. A setting in health promotion is anywhere people gather, work, live, play, worship or socialise (DH, 1995). The setting or venue for health promotion is best in an environment that participants are familiar with and where they can be supported by people they know (Hart, 2007). However, the fact that such health initiatives are not in existence may reflect the failure of mainstream health services to adequately provide for the health needs of people with intellectual disability in the community on equal terms with non-disabled people (Hart, 2007). Opportunities to work towards the achievement of goals and targets should be enhanced in various settings (DH, 1995), such as the place where people work. This allows health to be made an integral part of the organisational development and institutional change, rather than simply an add on (Kickbusch, 1989). However, within the community, most professional training in fitness and exercise does not cover coursework related to people with intellectual disability. As a result, these professionals are usually unfamiliar with ways of adapting fitness classes for people with intellectual disability or instructing them in using equipment properly (Rimmer, 2005). Therefore, the broader arena of health and fitness needs to become more aware and active in supporting people with intellectual disability whom they encounter. Within any programme or initiative, there should be an evaluation process and to address health promotion and obesity, evaluation should address general health aspects, knowledge, understanding and personal benefits.

**Evaluation methods**

Evaluation of the extent to which actions achieve a valued outcome (Green and Tones, 1999) should be assessed to identify changes in health, which can be attributed to the programme (Nutbeam, 1998). The evaluation methods used should consist of both pre and post-test, along with process/formative evaluation (range of formal and informal assessments during the process in order to modify activities and improve programme) and outcome/summative evaluation (assessment to identify achievement; summarises development and identifies weaknesses). Prior to commencing a programme, participants should attend their GP for health screening. Results of health screening are used as a baseline to compare pre/post (weight, BMI, blood pressure, blood glucose levels, cholesterol levels) and will be checked to evaluate the health promotion initiative or as a contraindication to certain physical activities. Effective screening must be married to health promotion opportunities in order to produce health gains (Marshall et al, 2003).

Owing to the client’s cognitive ability, checking whether communication has been understood is advisable by asking for feedback throughout the programme (Fraser and Fraser, 2001). This could be carried out using techniques such as Buzz groups, which promote interaction (Hafler, 2003), food diaries to record and evaluate nutrition, and role play as outlined by Lindsay and Michie (1998).
An impact evaluation, which relates to the immediate effect of a programme could also be carried out (Naidoo and Wills, 2009). This could involve re-administering the NAKS questionnaire to each participant to establish changes as a result of the programme (Ilivingworth et al, 2003). However, some benefits will only become apparent after a considerable period of time (known as the sleep effect (Nutbeam, 1998)). Contrary to this, the intervention may seem to have an immediate effect, but which decreases over time (backsliding effect (Nutbeam, 1998)). If evaluation takes place too late, the immediate impact will not be measured. Even if the early effect is observed, this cannot be assumed to last (Nutbeam, 1998). Therefore, outcome evaluation should be carried out at different periods during and following the programme.

**Conclusion**

Where the benefits of the health promotion initiative are well established, there is no need to ‘reinvent the wheel’; it is only where there is doubt about the effects and advantages of the initiatives that further programmes will need to be invented (Green and Tones, 1999). While health promotion in relation to obesity has been well researched within the general population, it is gaining greater impetus within intellectual disability, as what has been successful with the general population is not always transferable to people with a disability. Disseminating the findings of programmes in practice will provide a secure foundation on which to make decisions in planning future health promotion activity. Through the dissemination of findings of health promotion principles from practice, health professionals can recognise the value and contribution of effective strategies for people with intellectual disability and move towards evidence-based practice (Green and Tones, 1999). Owing to cognitive impairment associated with intellectual disability, providing an equitable and accessible service poses a challenge to service providers. A combined approach is warranted with a more comprehensive health behaviour education programme, incorporating exercise, nutrition information, community-based activities and support groups for adults with intellectual disabilities (Heller et al 2011).

**Key points**

- People with intellectual disability who are obese often experience limited opportunities for community participation, employment and leisure, while also requiring greater assistance with activities of daily living
- Information regarding health promotion needs to be in a clear and accessible format that contains information relevant to people with intellectual disability
- Health promotion needs to incorporate education, behaviour, empowerment and social change issues
- Social variables, such as friendships and recreational opportunities, are important alongside traditional aspects of health promotion, such as diet and physical activity

**References**


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