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# Caregivers' perception of factors associated with a healthy diet among people with intellectual disability living in community residences: A Concept mapping method



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#### ABSTRACT

*Background:* Many people with intellectual disabilities (ID) living in community-based residences have been found to have unhealthy diet and weight disturbances. In Norway, a majority of people with ID live in such residences.

Aims: The aim of the study was to examine factors affecting the caregivers' opportunity to promote a healthy diet among the residents.

Methods and procedures: A concept mapping methodology was adopted, including group-based brainstorming, idea synthesising, sorting, rating and analysis of the results. Informants were caregivers in four different community residences for people with mild to moderate ID in the southeast of Norway. A total of 13 informants were recruited (12 females and 1 male), and 10 informants completed two sessions.

Results: Eight clusters were identified as affecting the caregivers' ability to promote a healthy diet: "Availability and accessibility", "Guidance and autonomy", "Competence among staff", "Planning and involvement", "Customization", "External conditions affecting staff", "Legislation, rules and structure" and "Everyday challenges", each including both barriers and facilitators.

Conclusions and implications: Multiple factors affect the caregivers' ability to promote a healthy diet. Caregivers' opportunity to promote a healthy diet is complex. Availability and accessibility of healthy food is crucial, but a healthy diet also requires time and competence among the caregivers.

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#### What this paper adds

This study examines factors affecting caregivers' opportunity to promote a healthy diet among people with ID living in community residences, and adds a new perspective to the public health challenges of unhealthy diets and weight disturbances in these groups. Few studies have been conducted using the caregivers' point of view when examining these health challenges. In addition, this study has applied a relatively new methodology called concept mapping, which is considered

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effective for capturing a group's perspective and informants' points of view. The study result shows distinct action areas that can be used effectively in working with people with intellectual disabilities living in community residences.

#### 1. Introduction

The deinstitutionalization and establishment of community-based settings for people with intellectual disabilities (ID) in Norway was implemented in the 1990s. The intentions of the reform were to normalize the lives of people with ID, and to see and respect them as full-fledged citizens with the right to self-determination (Ministry of Children, Equality and Social Inclusion, 2012). Today all the institutions for people with ID in Norway are closed, with the law ensuring them the right to community services (Ericsson, 2002; Tøssebro, 2004). Furthermore, the service provision should not be linked to the residential unit, but should instead be customized to the individual resident based on his or her abilities and needs (Norwegian Ministry of Social Affairs, 1987). However, in practice, the service provided is determined by such factors as the number of staff, the organization of the residences and the education level among the caregivers, which is again related to the municipal economy and willingness to invest in this area (Eide & Breimo, 2013). This means that, despite good intentions, the deinstitutionalization of people with ID is associated with unexpected lifestyle challenges such as unhealthy diet and weight disturbance (Bryan, Allan, & Russel, 2000).

The International Statistical Classification of Diseases and Related Health Problems (ICD) defines ID as a condition with stagnated or deficient development of ability and capability (WHO, 1992). The term ID represents a wide spectrum, and individuals with ID have quite different needs for facilitation and monitoring (Norwegian Ministry of Social Affairs, 1990). An ID often implies difficulties dealing with the details of everyday life, while customization and enabling can help reduce limitations (The Norwegian Association for Persons with Developmental Disabilities, 2016). How the environment is tailored for these individuals is an important determinant that influences the quality of life and the individual need for care, regardless of the intellectual severity.

Traditionally, the health focus among people with ID has been directed towards the disease or disability itself, while prevention of secondary lifestyle-related diseases has not been given much attention (Hove, 2004; Nordstrøm, Hansen, Paus, & Kolset, 2013). More recently, disability has been linked to health inequality (Emerson & Hatton, 2007), and it has been suggested that the health status of people with ID living in community residences is worse compared to other groups (Heslop et al., 2013; Martínez-Leal et al., 2011, Rimmer, Braddock, & Marks, 1995). US and European studies show a higher prevalence of underweight, overweight and malnutrition among people with ID in comparison to the general population (Ministry of Children, Equality and Social Inclusion, 2012). In Norway, too, it appears that adolescents and adults with disabilities have a higher prevalence of overweight compared with the general Norwegian population (Hove, 2004). Several studies have identified poor diet and lack of physical activity as two risk factors which contribute to health differences among people with ID (Emerson & Baines, 2010; Sutherland, Couch, & Iacono, 2002). A study conducted in Norway found that a large proportion of persons with ID living in community residences frequently consumed precooked meals and showed a high frequency of soft drink consumption in comparison to persons with ID living with relatives (Nordstrøm, Paus, Andersen, & Kolset, 2015). These findings indicate that dietary behaviours must be reversed in order to improve the overall health condition of this group.

The study takes a closer look into community residences where the residents own or rent their own apartment. This type of community residence often has a common area for the residents and is staffed with permanent personnel (Eide & Breimo, 2013). The meals are prepared by the residents themselves or by the staff working with them. The residents have access to many types of food while the opportunity to buy and make their own food should be facilitated.

The Norwegian Ministry of Children, Equality and Social Inclusion argues that people with ID are in need of extra stimulation and facilitation concerning the promotion of a healthy lifestyle (Ministry of Children, Equality and Social Inclusion, 2012). At the same time, little research has been published that can uncover how to improve the dietary challenges in this group. One study conducted to explore the views of professionals working in group homes in Sweden found that important aspects for health promotion include: the residents' sense of security, knowledge among caregivers and motivation among the residents (Wahlström, Bergström, & Marttila, 2014). Furthermore, a study conducted in the UK found that greater ability and less restrictive residential settings are associated with poor diet and obesity (Robertson et al., 2000).

Self-determination implies that people have the opportunity and right to make choices that may eventually have adverse health consequences (Ministry of Children, Equality and Social Inclusion, 2013). Because people with ID may have limited cognitive ability for assessing the consequences of long-term poor food choices, these opportunities for making choices may have significant health consequences (Smyth & Bell, 2006). Both individual and social factors, such as staff and management, affect choice-making for people with ID (Smyth & Bell, 2006). Thus, in order to improve their health status, quality health services for people with ID should be implemented and provided within that community (Martínez-Leal et al., 2011).

Before initiating health promoting strategies, however, it is crucial to get to know the problem at hand (Fraser, Richman, Galinsky, & Day, 2009). It is therefore important to identify the broader determinants affecting the targeted health behaviour, such as the social and economic environment, the physical surroundings, and individual characteristics and behaviour (Contento, 2010; WHO, 2013).

Accordingly, the objective of this study is to identify factors that affect the caregivers' ability to promote a healthy diet among people with ID living in community residences in Norway. The research question is therefore: According to the

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