



The right to a health-promoting diet for people with intellectual disabilities

DEBATT

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Adults with an intellectual disability are faced with several health-related challenges associated with diet. For many, obesity and secondary diseases constitute a major health problem. A number of health-related non-compliances were recently identified in the municipal service provision for this group. The problems are complex, and better dietary interventions must be put on the agenda to ensure that this group of people have their statutory right to a health-promoting diet fulfilled.

People with intellectual disabilities make up a vulnerable group, with cognitive difficulties

and reduced coping abilities. Their life expectancy is also reduced, which should be seen in connection with their high prevalence of obesity and other dietary and metabolic diseases (1–3). For many, the intake of fruit, vegetables and fish is considerably less frequent than recommended, and we have noted high consumption of ready meals and soft drinks among those who live on their own (2).

A recent national inspection of residential properties for people with intellectual disabilities found failings, some of them severe, with the services provided by 45 of 57 local authorities. The service provision was often found to be insufficiently systematic, and many employees were poorly informed about the people they were employed to assist (4, 5).

Intellectual disabilities are often caused by genetic changes that involve considerable differences in the incidence of comorbidity (2, 3, 6). Due to the many clinical variables, the people who make up this group cannot all be put in the same category and offered the same type of intervention. Those whose diagnoses are rare, are nevertheless marginalised by the specialist health service and by research (7). Many conditions require nutritional expertise which is not available within the municipal system of service provision.

The seriousness of the situation is deepened by the fact that there is no robust national overview of this group. According to the report entitled *På lik linje* [On equal terms], a total of 24 000 people with intellectual disabilities have been registered in Norway, yet the real number has been estimated at possibly 125 000 (8). There is very little research available on dietary initiatives directed at these people.

Guidelines and legislation

Most people with intellectual disabilities have a reduced capacity to make rational choices and to grasp the long-term consequences of an unfortunate lifestyle. This can result in significant weight increase and substantially greater health risks.

The quality regulations for the Norwegian Act relating to Municipal Health and Care Services, stipulate that '[...]the municipality (must) draw up written procedures to ensure that the users of nursing and care services have their basic needs met (...) such as sufficient nutrition (food and drink), a varied and health-promoting diet and reasonable dietary choice' (5).

The intellectual functioning of people in this group is globally impaired, and in adults with a moderate to mild intellectual disability, their capacity level, measured by neuropsychological testing, equals that which is expected in children aged 6–12. Their cognitive difficulties make it important that they receive appropriate guidance to ensure they have a good diet. How long are we meant to sit back and watch this group of vulnerable people ruin their own health within a publicly-run health and care system before we intervene?

The right to a health-promoting diet should be defined as a basic need that must be met if we are to provide a safe standard of services. Consequently, it is important to establish guidelines and procedural requirements that support proactive and health-promoting dietary initiatives in the primary care sector (box 1). This means day-to-day assistance with the buying and cooking of food, help to make sure that portion sizes are appropriate, limiting the intake of sweets and treats – and increasing the level of physical activity.

Proactive initiatives will reduce the need for more radical dietary/nutritional interventions.

Box 1 Proposed focus areas for nutritional work among people with intellectual disabilities

Better national overview of the situation

Clearer distribution of municipal responsibilities and better organisation of dietary initiatives

Increased nutritional expertise among service providers and people with intellectual disabilities

The increased incidence of obesity and unhealthy diets in this group may suggest that our health and care services have insufficient knowledge and inadequate procedures in this area. For instance, there is no tool that specifically facilitates dietary screening of this group. If a person with an intellectual disability is at risk of doing serious damage to his/her own health as a consequence of malnutrition, the highest-ranking municipal officer-in-charge can, under Chapter 9 of the Act relating to Municipal Health and Care Services, liaise with the specialist health service and the County Governor to decide that coercive measures should be taken. This may involve interventions such as restricting the purchase of sweets, sugary drinks and ready meals, and the locking of fridges.

Over time an unhealthy diet can cause considerable harm to a person's health, but the legislation is rarely interpreted with this in mind. Instead, the immediate risk of injury has been given prominence rather than the proactive initiatives that may prevent such harm in the longer term, for example due to a significant weight increase. This means that structured dietary initiatives are often introduced at an unnecessarily late stage.

Organising the nutritional work

If we are to achieve sound, holistic solutions, cooperation is imperative, with an exchange of knowledge among nutritional experts, social educators, psychologists, physiotherapists and medical doctors. According to the new National Action Plan for a Better Diet (2017–21) the main responsibility for systematic health-promoting nutritional work among people with intellectual disabilities clearly lies with the Ministry of Health and Care Services.

In practice, the work to improve diets should be organised in partnership with the regional health authorities' habilitation services (9). There is a need for more clinical dietitians who specialise in intellectual disabilities. To enable dietitians to assist the municipal service providers, there is a need for knowledge about behavioural therapy interventions based on lifestyle change (10). In addition, we need expertise relating to rare syndromes and diagnosis-specific dietary treatments (6). An annual health check with a general practitioner will also be an important initiative.

People with intellectual disabilities make up a vulnerable group and it is challenging for them to take responsibility for their own diet. Improving the nutritional status of this group is a matter of national importance, based on their equal right to good health and equal access to evidence-based healthcare services for all.

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