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Use of health and dental care services in adults with intellectual disability in relation to age and intellectual disability levels

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ABSTRACT

Background: This study investigates the use of health and dental care services in adults with intellectual disability in the last 12 months according to Norwegian recommendations and in relation to age and intellectual disability levels.

Method: A cross-sectional community-based survey including 214 participants (56% men). POMONA health indicators were used for data collection.

Results: Health checks and contact with general practitioners in the last year increased with age but were less frequent in those with more severe intellectual disability. Hospital admissions were age independent. Less than one-fifth of women had undergone cancer screening, with small variations according to intellectual disability severity levels. Few had an individual plan. More than one-third experienced poor dental health despite frequent controls.

Conclusions: The use of health checks was lower than recommended, especially in individuals with more severe intellectual disability. Service access and individual plan use need to be enhanced, and dental care services should be improved.

Trial registration: [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT03889002) identifier: NCT03889002

KEYWORDS

Intellectual disability; healthcare services; individual plan; dental care services

United Kingdom (UK) based population studies on people with intellectual disability confirm higher rates of physical health disorders (Kinnear et al., 2018), increased mortality rates (McCarron et al., 2015), and poor general health (Dunham et al., 2018) compared to the general population. Health conditions like epilepsy, constipation, and obesity are some of the most prevalent conditions in people with intellectual disability compared to people without this diagnosis (Cooper et al., 2015; Folch et al., 2019). Moreover, higher frequencies of several health conditions are found in individuals with severe intellectual disability compared to those with milder intellectual disability (Cooper et al., 2018; Kinnear et al., 2018; Olsen et al., 2021; Perera et al., 2019).

Despite adults with intellectual disability having poorer health than the general population, they have

less access to healthcare services and health-promoting activities (Cooper et al., 2018; Reppermund et al., 2019). According to the supervision of the Norwegian county governors in 2016, there were challenges attached to sound healthcare services at home and access to general practitioner (GP) assessment (Norwegian Board of Health Supervision, 2017). Internationally, health checks have been recommended as part of a health policy response to reduce the health inequities experienced by people with intellectual disabilities (Buszewich et al., 2014; Robertson et al., 2014). General health checks are performed by health professionals and involve several screenings, but have not been found to prevent morbidity and mortality from disease in the general adult population (Krogsbøll et al., 2019). However, health checks by GPs among individuals with

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intellectual disability are effective in identifying unrecognised healthcare needs (Durbin et al., 2019; Robertson et al., 2014). National guidelines regarding better primary care for individuals with intellectual disability in Canada, the UK, and recently also in Norway (Byrne et al., 2016; Maltais et al., 2020; Norwegian Directorate of Health, 2021; Public Health England, 2017) recommend annual health checks.

Approximately one-third of the participants in a Canadian study reported not having undergone a comprehensive medical examination in the last year, inconsistent with best practice guidelines (Maltais et al., 2020). McConkey et al. (2015) found that adults with intellectual disability who had a health check were significantly older than those who had not; further, the rates of hospitalisation, physiotherapy, and dental care increased with age (McCarron et al., 2017). In a Norwegian study, adults with intellectual disability were more frequently hospitalised at a younger age compared to the general population (Skorpen et al., 2016). Although people with intellectual disability received primary care at a similar rate as people without intellectual disability in the US (Haverkamp & Scott, 2015), or even at a higher rate in the UK (Carey et al., 2016) and Ireland (McCarron et al., 2017), they were significantly less likely to receive a mammogram (Haverkamp & Scott, 2015).

Few studies – only one in Nordic countries (Mrayyan et al., 2021) – have investigated how the use of healthcare services varies with levels of intellectual disability. McConkey et al. (2015) found no differences in the use of health checks in terms of intellectual disability level. Others report more prominent inequities, such as fewer psychiatry services and cancer screenings for women, among individuals with more severe levels of intellectual disability (Folch et al., 2019; Maltais et al., 2020).

Good oral health is important for wellbeing and influences general health (Hsieh et al., 2018; Wilson et al., 2019). Although poor oral health is preventable through proactive oral care support, it is common in individuals with intellectual disability (Finkelman et al., 2013; Ward et al., 2019), with oral problems increasing with intellectual disability severity (Olsen et al., 2021). Moreover, with regard to dentistry, Wilson et al. (2019) found that people with intellectual disability receive significantly less preventive services and have poorer access to services than those without intellectual disability. Consequently, regular preventive oral actions are recommended in Norway (Norwegian Directorate of Health, 2021).

The co-occurrence of physical health disorders and intellectual disability raises challenges for staff working

in municipality and specialised healthcare services because of the additional complexity in assessments and interventions (Dunn et al., 2020). In some countries, this area has received little attention (Dunn et al., 2020); hence, GPs may feel isolated (Bakker-van Gijssel et al., 2017; Fredheim et al., 2013). The organisation of healthcare services for people with intellectual disability in Norway is a shared responsibility between GPs, standard medical specialties, and specialised multidisciplinary hospital-based intellectual disability services with outpatient clinics and ambulatory functions. At the municipality level, individual plans (IP) are a statutory right for individuals with disability who need coordination of multiple services (Norwegian Directorate of Health, 2015); however, the degree of implementation for adults with intellectual disability is unknown. More information about the use of regular health assessments, other treatments, and preventive actions for this population is needed to develop better healthcare services (Durbin et al., 2019).

Therefore, this study aims to investigate the use of health and dental care services in the last 12 months among adults with intellectual disability according to national recommendations and in relation to age and level of intellectual disability. A secondary aim is to explore the use of dental care services in relation to experienced access to dental care, pain in the mouth, and experienced good or poor dental health.

Methods

Study design and setting

This cross-sectional multicentre study included five municipalities in the northern and central regions of Norway (Tromsø, Balsfjord, Narvik, Malvik, and parts of Trondheim). Most municipalities in Norway are a mix of scattered settlements and urban areas, with varying distances to specialised habilitation services for individuals with intellectual disability. The number of inhabitants of the municipalities included in this study are as follows: 5593 (Balsfjord), 13371 (Malvik), 18705 (Narvik), 71590 (Tromsø), and 182035 (Trondheim, the third largest municipality in Norway) (Statistics Norway, 2014). Specialised intellectual disability services and hospitals are located in the cities of Tromsø, Narvik, and Trondheim; most inhabitants of the included municipalities can reach these within one and a half hours. The distance to a centre with specialised health services is often longer for other inhabitants in Norway. The study was led from the University Hospital of North Norway

(UNN) in Tromsø in close cooperation with St. Olavs Hospital in Trondheim.

Procedure

Potential participants aged 16 years or older and living in the defined areas were identified through specialised intellectual disability services at the hospitals or through employees in the municipalities who have an overview of all adults with intellectual disability who receive some sort of municipal services. An invitation letter for the study was sent to each eligible person registered in the specialised intellectual disability services records at the UNN and St. Olavs Hospital. Moreover, eligible individuals who were not registered at the hospitals' specialised intellectual disability services were directly contacted by municipality employees through invitation letters and/or over the telephone. The user organisations and administrative leaders of the services in the municipalities were informed about the study.

In Norway, minors 16 years and above essentially can consent to research (The Norwegian National Research Ethics Committees, 2022). Comprehensive information sheets regarding the study, including an easy-to-read version, were provided to all potential participants. As far as possible, we customised the information to the individuals' level of functioning. Written informed consent was obtained from each individual; when that was not possible, it was obtained from their legal representative. To avoid uncertainty in consent competence, a support person often consented together with the person with intellectual disability, unless the person with intellectual disability clearly demonstrated consent capacity and chose to participate alone.

Data were collected between October 2017 and December 2019 by research assistants with a health professional background (research nurses, intellectual disability nurses, and one physiotherapist) via structured interviews and questionnaires from the participants and/or their next of kin, caregivers, or support person. Regular meetings on Skype among the researchers were held to clarify doubts and to ensure the collection of quality data.

Study approval

The study was approved by the Committee for Medical Research Ethics, Health Region North (2017/811) and the data protection officer at the UNN and St. Olavs Hospital. The trial is registered in ClinicalTrials.gov with identification number NCT03889002 in accordance with UNN guidelines.

Development of the POMONA-15 survey instrument

The internationally developed POMONA-15 (P15) health indicators (Perry et al., 2010) were used to investigate demographics, use of healthcare services, dental health, and physical health conditions as described below for each outcome. The P15 was developed by a partnership of 13 EU member states to investigate health disparities in individuals with intellectual disability compared to the general population (Perry et al., 2010). The specific items used to measure the health indicators were largely taken from existing European Health Interview surveys used in the general population. As described in the original publication from 2010, the P15 was translated into and back-translated to 13 languages, including Norwegian. The translated Norwegian version was used in the original data collection in the POMONA project (Perry et al., 2010). Where possible, internal consistency and interrater reliability were explored in the original project. The P15 was found to overall have acceptable feasibility, internal consistency, and face validity (Perry et al., 2010).

Demographics, level of intellectual disability, and syndrome diagnosis

Age, gender, and living conditions were registered. Participants' living conditions were categorised as living alone, with family, or in apartments with closely available care services (Molden et al., 2009). Information about the levels of intellectual disability and concurrent conditions of autism spectrum disorder and Down syndrome was confirmed in the participants' medical records. The levels of intellectual disability were categorised as mild (intelligence quotient (IQ) = 50–69), moderate (IQ = 35–49), severe (IQ = 20–34), or profound (IQ = <20) (World Health Organization (WHO), 2019). For eight individuals without registered levels of intellectual disability, the level of intellectual disability was determined from information about adaptive functioning in cooperation with specialised intellectual disability health staff (Tassé et al., 2019).

Physical health conditions

As part of the P15 structured interview, a physical health condition was registered if the participants had the condition during the last year or if it was chronic (Olsen et al., 2021). Multimorbidity was defined as having one or more physical health condition in addition to the intellectual disability diagnosis (WHO, 2016).

Table 1. Health and dental care services.

Variables	Questions asked	Coded responses		
Health check (<i>n</i> = 214)	When did you last have a full medical assessment?	Yes, health check during last year (57%)	No health check last year (34%)	Cannot answer (9%)
General practitioner (GP) visits (<i>n</i> = 214)	During the last 12 months, approximately how many times have you been to or had a one-to-one visit by your GP (or other doctor)?	Yes, GP visit last year (84%)	No GP visits last year (13%)	Cannot answer (3%)
Hospital stay (<i>n</i> = 214)	During the last year, did you stay one or more nights at the hospital?	Yes (16%)	No hospital stay (83%)	Cannot answer (<1%)
Hospital day visit (<i>n</i> = 214)	During the last year, did you receive treatment at the hospital without spending the night?	Yes (49%)	No hospital day visit (51%)	Cannot answer (<1%)
Mental health (<i>n</i> = 214)	During the last 12 months, approximately how many times have you been to a psychologist, psychiatrist, or other similar doctor?	Yes, one or more visits (17%)	No visits (81%)	Cannot answer (2%)
Physiotherapy (<i>n</i> = 214)	During the last 12 months, approximately how many times did you see a physical therapist?	Yes, one or more visits (18%)	No visit (82%)	Cannot answer (<1%)
Specialised habilitation services (<i>n</i> = 214)	During the last 12 months, did you receive any follow-up by the specialised habilitation unit?	Yes (49%)	No (50%)	Cannot answer (1%)
Individual plan (<i>n</i> = 203)	Does you have an individual plan?	Yes (40%)	No (57%)	Cannot answer (3%)
<i>Women (n = 95)</i>				
Breast examination (<i>n</i> = 95)	Did you get a breast examination during the last year?	Yes (16%)	No (80%)	Cannot answer (4%)
Mammography (<i>n</i> = 95)	When did you last get a mammography?	Ever (16%)	Never (78%)	Cannot answer (6%)
Cervical cancer (<i>n</i> = 95)	Have you been screened for cervical cancer during the last three years?	Yes (18%)	No (76%)	Cannot answer (6%)
Dental care services (<i>n</i> = 214)	How many times did you visit a dentist or dental nurse during the last 12 months?	One or more times last year (94%)	No visits (6%)	Cannot answer (<1%)
	Do you have access to a dentist or dental nurse when you need it?	Yes (68%)	No (30%)	Cannot answer (2%)
Dental health (<i>n</i> = 214)	Do you have pain in your mouth or teeth?	Yes (24%)	No (70%)	Cannot answer (6%)
	How is your dental health?	Good: Very good/good (61%)	Poor: Fair/poor/very poor (39%)	Cannot answer (<1%)

Questions asked and coded responses.

Use of healthcare services

The use of healthcare services was identified by whether the participant received the service during the last 12 months or not, or was unable to answer. As we chose to focus on known use of healthcare services, the variables were dichotomised into use of healthcare service or no identified use of service. The services included were annual health checks, GP visits, hospital admission, hospital day visit, contact with mental health professionals, physiotherapy, specialised habilitation service, and breast and cervix examination for women. The questions with code response options are presented in Table 1. A visual comparison of a similar Canadian study (Maltais et al., 2020) was made to compare the use of healthcare services in Norway with other countries.

Dental care

Use of dental care service was examined with the questions, “How many times did you visit a dentist/dental nurse during the last 12 months?” and “Do you have access to a dentist/dental nurse when you need it?”

Dental health was examined with the questions, “Do you have pain in your mouth or teeth?” and “How is your dental health?” Information about the variables with coded response options is presented in Table 1.

Individual plan

In Norway, an IP is a planning document and a structured collaboration process. It is a written document between the municipality services and the service user, their family, or guardian about the disability services

to be delivered to meet the service user's identified goals. According to the Norwegian Directorate of Health (2015), the plan should be updated continuously and be a dynamic tool in the coordination and targeting of the service offered. Persons in need of long-term and coordinated services in several areas of life have a statutory right to an IP (Norwegian Directorate of Health, 2015). This aspect was added after the pilot study, resulting in 203 participants who were asked related questions in the current study. The questions asked were, "Do you have an IP?" (yes/no) and "If yes, when was the IP last evaluated?" (during the last year/during the last two years/more than two years ago).

Data analysis

All analyses were conducted using SPSS Statistics for Windows version 26.0. Summaries of the participant characteristics are provided using number and percentage, mean and standard deviation (SD), or median and range. Frequency data were derived to determine prevalence rates of the use of healthcare services. The demographic variable age had acceptable normal distribution checked with skewness and kurtosis. However, visual inspection indicated a tendency to a bimodal distribution, which supported the division into three age groups.

The healthcare services – health checks, GP visits, hospital admission, hospital day visit, mental health professional, physiotherapy, specialised habilitation services, and preventive procedures (cancer screenings) – were operationalised into (1) use of healthcare services during the last 12 months or (2) no use of healthcare services during the last 12 months (no service/cannot answer).

Possible associations between the categorical variables, that is, use/non-use of each healthcare service and three age groups, were investigated with Pearson's chi-square test. For statistically significant associations post hoc analyses with cross tabulation were performed to identify the exact between-group differences.

As the use of healthcare services increased with age, possible associations between the use/non-use of each of the healthcare services as the dependent variable and levels of intellectual disability (mild, moderate, and severe/profound) were examined with several logistic regression analyses adjusted for age. Dummy variables of the three levels of intellectual disability on an ordinal scale were created with "mild intellectual disability" as the reference category. Variables associated with having/not having an intellectual disability (dependent variable) were investigated with multivariable binary logistic regression analysis with backward

removal of statistical insignificant variables ($p > .05$). Independent variables entered were age, gender, and levels of intellectual disability (mild, moderate, severe/profound). Multicollinearity was checked with bivariate correlation between independent variables with .7 as the cut-off value (Dormann et al., 2012), in addition to control of the variance inflation factor. Model fit was investigated with the Hosmer–Lemeshow test.

The association between dental care services received in the last 12 months (yes/no) and the variables, such as dental care when needed (yes/no), pain in mouth/teeth (yes/no), and dental health (good/poor), were investigated by the chi-square test or Fisher's exact test when appropriate.

The level of statistical significance was set at $p < .05$. We did not adjust for multiple testing across the different univariable and logistic regression analyses, however to compensate we have provided all corresponding odds ratio (OR), standard errors, exact p -values and 95% Confidence Interval (CI). The comparisons were planned and all comparisons were reported (Rothman, 1990).

Results

Participant characteristics

All persons with a verified diagnosis of intellectual disability according to the International Statistical Classification of Diseases and Related Health Problems 10th revision criteria (WHO, 2019) were invited to participate in this study. The sample comprised 214 individuals with intellectual disability, of whom 56% were men. The age range was 16–78 years (mean = 36.1 years; SD = 13.8). Additionally, 48 (22%) were diagnosed with autism, 40 (19%) with Down syndrome, and 24 (11%) with cerebral palsy. Information on intellectual disability level was available for 205 participants. The distribution of intellectual disability levels was: mild 82 (38%), moderate 56 (26%), severe 50 (24%), profound 17 (8%), and unknown 9 (4%). A total of 169 (79%) participants had multimorbidity (Table 2). In Olsen et al.'s (2021) study with the same sample, autism, epilepsy, and constipation were significantly more prevalent in individuals with severe and profound intellectual disability than in those with less severe intellectual disability levels. As described by Olsen et al. (2021), some individuals were excluded because circumstances made it hard to obtain valid information or the intellectual disability diagnosis was withdrawn.

Information about eligible non-participants was available only in the northern region; there were 266 eligible individuals (140 participants and 126 non-

Table 2. Population characteristics ($N = 214$).

	Total $N = 214$
Gender, n (%)	
Men	119 (56)
Women	95 (44)
Age (years), mean (SD)	36.1 (13.8)
Median (range)	32.5 (16–78)
Level of intellectual disability*, n (%)	
Mild	82 (38)
Moderate	56 (26)
Severe	50 (24)
Profound	17 (8)
Unknown	9 (4)
Number of physical health conditions, mean (SD)	2.1 (1.5)
Multimorbidity, n (%)	169 (79%)
Living condition, n (%)	
Lives independently	25 (12)
Lives with family	41 (19)
Own apartment attached to family house	2 (1)
Group home with care	146 (68)

SD: standard deviation.

participants; participation rate = 53%). The participants were younger (mean age = 35.3; SD = 14.1) compared to the non-participants (mean age = 42.3 years; SD = 15.9) ($p < .001$), while the gender distribution was similar across the two groups. In the central region of Norway, valid information about non-participants was not available. However, there were lower participation rates, resulting in a sample of 74 participants who had a similar distribution of age and gender as in the north.

Use of healthcare services in the last 12 months related to age

Tables 1 and 3 show that 57% of the participants had undergone a health check during the last 12 months. It appears that more of the older participants (73%) had received a health check than the younger age groups

(48% and 53%) (chi-square test, $p = .006$). In post hoc between-group analyses there were statistically significant more use of health checks in those above 45 years than in each of the two younger age groups. Moreover, 84% of all participants had consulted their GPs in the last 12 months. The apparent significant difference in GP visits was between the youngest (76%) and the oldest (94%) age groups. In total, 18% of the women had undergone a cervical cancer examination the last 3 years. No age differences were observed in hospital admission, hospital day visit, use of mental health professionals, physiotherapy, specialised intellectual disability services, or cervical cancer examination for women.

Table 3 also shows the use of healthcare services in the study by Maltais et al. (2020), which has a comparable age distribution with our study. Compared to the Canadian study, apparently fewer Norwegian participants reported having undergone comprehensive medical examinations in the last year, and screening for cancer in women was less frequently performed in Norway. The comparison is visual; we were not able to compare the groups statistically.

Use of healthcare services in the last 12 months related to intellectual disability level

As shown in Table 4, in the age-adjusted binary logistic regression analysis, fewer individuals with severe/profound intellectual disability (49%) had undergone a health check in the last 12 months than those with mild intellectual disability (65%), (OR 2.11, 95% CI 1.07–4.15, $p = .031$). The difference in use of health checks between individuals with mild intellectual disability (65%) and moderate intellectual disability (54%) was not statistically significant (OR 1.63, 95% CI .81–3.28, $p = .175$).

Table 3. Use of healthcare services the last 12 months related to age ($N = 214$).

	Age ≤ 29 $n = 86$	Age 30–44 $n = 62$	Age ≥ 45 $n = 66$	Total $N = 214$	p -value ^a	Maltais et al. (2020)
Health check, n (%)	41 (48%)	33 (53%)	48 (73%)	122(57%)	.006	70%
General practitioner, n (%)	65 (76%)	53 (85.5%)	62 (94%)	180(84%)	.008	
Hospital stay, n (%)	15 (17%)	10 (16%)	10 (15%)	35 (16%)	.929	
Hospital day visit, n (%)	44 (51%)	29 (47%)	31 (47%)	104(49%)	.827	
Mental health professional, n (%)	18 (21%)	9 (14.5%)	9 (14%)	36 (17%)	.417	15% ^b
Physiotherapy, n (%)	15 (17%)	16 (26%)	8 (12%)	39 (18%)	.130	4%
Specialised habilitation services, n (%)	40(46.5%)	29 (47%)	36 (54.5%)	105(49%)	.563	
Dental care services	80 (93%)	60 (97%)	61 (92%)	201(94%)	.708	56%
Women	$N = 36$	$N = 28$	$N = 31$	Total $n = 95$		
Breast examination last year	3 (8%)	3 (11%)	9 (29%)	15 (16%)	.023	
Mammography anytime	1 (3%)	1 (4%)	13 (42%)	15 (16%)	<.001	61% ^c
Cervical cancer examination last 3 years	3 (8%)	6 (21%)	8 (26%)	17 (18%)	.061	47%

^a p -values are tests in the present study of associations between use/non-use of healthcare services and age groups with Pearson's chi-square test (two-sided).

^bPercent of consultation within psychiatry.

^cMammogram in the last two years, women aged 50–69.

Proportions in the current study are compared to utilisation in the last year in a Canadian study (Maltais et al., 2020).

Table 4. Use of healthcare services the last 12 months related to level of intellectual disability in 205 participants.

	Total n = 205 n (%)	Mild intellectual disability n = 82 n (%)	Moderate intellectual disability n = 56 n (%)	Severe/Profound intellectual disability n = 67 n (%)	p-values Adj. age Moderate intellectual disability/severe or profound intellectual disability (Mild intellectual disability ref.)
Health check	116 (57%)	53 (65%)	30 (54%)	33 (49%)	.175/.031 ^a
General Practitioner	172 (84%)	73 (89%)	49 (87.5%)	50 (75%)	.760/.007 ^a
Hospital stay	34 (17%)	14 (17%)	8 (14.3%)	12 (18%)	.671/.824
Hospital day visit	100 (49%)	39 (48%)	24 (43%)	37 (55%)	.600/.296
Mental health professional	35 (17%)	20 (24%)	6 (11%)	9 (13%)	.051/.144
Physiotherapy	37 (18%)	18 (22%)	9 (16%)	10 (15%)	.407/.366
Specialised habilitation services	101 (49%)	41 (50%)	24 (43%)	36 (54%)	.410/.650
<i>Women</i>	<i>Total</i>				
	n = 92	n = 44	n = 22	n = 26	
Breast examination last year	15 (16%)	6 (14%)	2 (9%)	6 (23%)	.498/.686
Mammography anytime	15 (16%)	4 (9%)	3 (14%)	8 (31%)	.714/.288
Cervical cancer test in the last three years	17 (18%)	9 (20%)	3 (14%)	5 (19%)	.408/.539

^aOdds ratios and 95% confidence intervals are provided in the manuscript text. Reference group: Mild intellectual disability. p-Values are adjusted for age in binary logistic regression analyses with mild intellectual disability as the reference category.

Additionally, fewer individuals with severe/profound intellectual disability (75%) had consulted their GPs than those with mild intellectual disability (89%) (OR 0.28, 95% CI .11–.71, $p = .007$). The narrow 95% CI for the OR may indicate low data variability. No difference in GP visits was found when comparing individuals with moderate intellectual disability (87.5%) with those with mild intellectual disability (89%) (OR .85, 95% CI .29–2.47, $p = .760$).

There were no statistically significant associations between levels of intellectual disability and hospital treatments, services from specialised intellectual disability teams, physiotherapy, use of mental health professionals, or preventive procedures such as breast examination, mammography, or cervical cancer examination (Table 4).

Access to and evaluation of the individual plan

Of the 203 participants answering the question about having an IP, 77 (40%) reported having an IP and 57% had no IP. As shown in the final model of the logistic regression analysis in Table 6, participants who reported having an IP were younger than those without (33.8 vs. 39 years) and more frequently had a severe/profound level of intellectual disability than mild intellectual disability ($p = .049$). Of those with an IP, 40% had severe/profound intellectual disability, and among those without an IP, 28% had severe/profound intellectual disability. There was no gender difference in having/not having an IP. Of the 77 participants with an IP, only 27 had had it evaluated in the last year. This

means that around 13% of all participants had an IP with at least yearly evaluations (Table 5).

Dental care services during the last 12 months in relation to age, gender, level of intellectual disability, access to dental care, perceived pain in mouth/teeth, and experience of poor dental health

The frequency of use of dental care services, defined as seeing either a dentist or a dental nurse, was 94% in the last 12 months; there were no age and gender differences. Individuals with severe/profound intellectual disability tended to have a higher risk of not using dental services (10%) than those with milder levels of intellectual disability (4%) ($p = .093$). Of the participants, 32% had no access to dental care when needed, 25% had pain in the mouth/teeth, and 39% perceived their dental health as poor (Table 6). More among those not

Table 5. Having an individual plan as the dependent variable in a binary logistic regression analysis.

Variable	Adjusted odds ratio	95% CI for OR	p-value
Age	.96	0.94–0.99	.003
Moderate intellectual disability ^a	1.48	0.71–3.12	.300
Severe/profound intellectual disability ^a	2.38	1.16–4.86	.018

^aLevels of intellectual disability: Mild intellectual disability (reference category), moderate intellectual disability, severe/profound intellectual disability.

Final model with age as continuous variable and mild intellectual disability as the reference category for the participants' levels of intellectual disability.

Table 6. Dental care services during the last 12 months in relation to gender, age, level of intellectual disability, access to dental care when needed, pain in mouth/teeth, and perceived dental health.

	Total N = 214	Dental care service in the last 12 months n = 201	No dental care service in the last 12 months n = 13	p-value
Gender				
Men	119 (56%)	111 (55%)	8 (62%)	
Women	95 (44%)	90 (45%)	5 (38%)	.657 ^b
Age				
≤29	86 (40%)	80 (40%)	6 (46%)	
≥30	128 (60%)	121 (60%)	7 (54%)	.651 ^b
Access to dental care when needed	145 (68%)	140 (70%)	5 (38%)	.030 ^a
Pain in mouth/teeth	53 (25%)	48 (24%)	5 (38%)	.332 ^a
Level of intellectual disability	Total n = 205	n = 192	n = 13	
Mild/moderate	138 (67%)	132 (69%)	6 (46%)	
Severe/profound	67 (33%)	60 (31%)	7 (54%)	.093 ^b
Dental health	Total n = 213	N = 200	N = 13	
Good	130 (61%)	125 (62%)	5 (38%)	
Poor	83 (39%)	75 (38%)	8 (62%)	.085 ^b

^aCross-tabulation with Fisher's exact test (exact sig. two-sided).

^bChi-square test.

receiving dental care reported not having access to dental care when needed. Experience of poor dental health tended to be more frequent among individuals with no dental care services in the last 12 months (62%) than among those receiving dental care services (38%) ($p = .085$).

Discussion

In this Nordic study on the use of healthcare services in adults with intellectual disability, about half of the participants (57%) had undergone a health check during the last 12 months. Notably, individuals with more severe intellectual disability levels had been to a health check and seen a GP significantly less in the last 12 months than those with mild intellectual disability levels. The use of healthcare services, in general, increased with age, but contrary to our expectations, hospital admittance did not. Few women had received cancer screening of the breast or cervix. Even though 94% of the participants had been to a dentist or dental nurse in the last 12 months, 32% reported not having access to dental care services when needed, and 39% experienced poor dental health. There tended to be a significant association between not receiving a dental check and experience of poor dental health as well as having severe/profound intellectual disability.

The use of annual health checks in adults with intellectual disability in the current study is in line with the reported rates of 50–70% in the UK, Spain, and Canada (Folch et al., 2019; Maltais et al., 2020; McConkey et al., 2015; Perera et al., 2019). These findings are inconsistent with the current consensus on best practice guidelines for primary care practice with intellectual disability in the UK, Canada, and Norway (Maltais et al., 2020; Norwegian Directorate on Health, 2021;

Perera et al., 2019). For individuals with intellectual disability, health checks are clinically useful and cost-effective as they may reveal health disorders, leading to the initiation of treatments (Cooper et al., 2014; Hanlon et al., 2018). As 79% of our participants had known multimorbidities, they may be at risk of developing further complications that remain undetected if not followed up regularly. However, GP visits were more frequent in the last year than annual health checks, consistent with the literature (Folch et al., 2019; McCarron et al., 2017). Although GP visits were relatively high, the literature implies that GPs may lack competence in treating individuals with intellectual disability (Fredheim et al., 2013).

The increasing health checks and GP consultations with age was not unexpected and is consistent with the findings from Northern Ireland and Ireland-based studies (McCarron et al., 2017; McConkey et al., 2015). In the study by Skorpen et al. (2016), hospital admissions of people with intellectual disability did not increase above 65 years, which contradicts the findings in the general population. This could indicate the underuse of specialised healthcare services among older individuals with intellectual disability in Norway, associated with limited organised health checks by GPs, the ability to express health problems compared to the general population, and problems with access to specialised medical care in hospitals.

Health checks and GP visits were more common among those with milder intellectual disability levels, in line with findings from Spain and Canada (Folch et al., 2019; Maltais et al., 2020). The greater prevalence of epilepsy and obstipation in individuals with severe/profound intellectual disability (Olsen et al., 2021) should lead to higher level of medical follow-up. Folch et al. (2019) found hospitalisation and the use of

physiotherapy to be more common among those with severe and profound intellectual disability, while we did not find such differences. From our clinical experience, the use of physiotherapy is less accessible in adults with intellectual disability, particularly in individuals with severe and profound intellectual disability. Our findings could imply an underuse of health services.

GP-led health checks are the most effective intervention and lead to significantly more clinical activities, such as vision testing (Byrne et al., 2016). Generally, people with intellectual disability often receive more services than the general population (Folch et al., 2019; Maltais et al., 2020; McCarron et al., 2017) but not in the management of long-term conditions (Cooper et al., 2018). GPs and other health professionals need to enhance their competence regarding intellectual disability (Fredheim et al., 2013). The collaboration between GPs and daily service providers could be improved, for example, by planning assessments together in advance. During the assessment, using visual communication tools could help individuals with intellectual disability understand what is going on. A primary health team where nurses cooperate with GPs in patient groups and home visits can facilitate a more holistic health follow-up (Ruud et al., 2020). Furthermore, physiotherapists could perform home visits and guide service providers.

Dental care services

The Norwegian national guidelines recommend annual dental health checks in individuals with a higher risk of dental health problems (Norwegian Directorate of Health, 2021). Most participants (94%) in the present study had visited a dentist or dental nurse in the last 12 months, a higher proportion than in the general Norwegian population (80%) (Jiang et al., 2021). Several studies report that individuals with intellectual disability are more likely to have seen a dentist compared to those without intellectual disability (Finkelman et al., 2013; Haverkamp & Scott, 2015; McCarron et al., 2017). In the Spanish study by Folch et al. (2019) and the Canadian study by Maltais et al. (2020), only approximately 50% had visited a dentist the previous year. In Norway, access in the general population is likely to be limited by economic constraints (Jiang et al., 2021), while dental care services for individuals with intellectual disability are free. Nevertheless, 32% in the present study reported not having access to dental care services when needed, and 39% experienced poor dental health. According to Wilson et al. (2019) and Olsen et al. (2021), a greater degree of intellectual disability predicts poorer oral health; however, in the present study, use of dental

care services tended to be less frequent in adults with more severe intellectual disability. Regarding age, no significant differences in annual dental care services were found. Despite recommendations of regular dental checks and municipality-based oral care, difficulties may arise owing to pain, communication, or collaboration problems.

Competence in successfully treating people with intellectual disability must be improved, preferably through a collaboration between the individual, relatives, and specialised dental health services and health professionals. In addition, prevention of dental problems, including dietary advice, must become a natural part of the support from childhood.

Individual plan

Only 40% of the participants reported having an IP, and 13% had a functioning IP with regular evaluations. An IP has been a statutory right for Norwegian individuals in need of long-term and coordinated services since 2001. However, this is not the reality for everyone in need of rehabilitation or habilitation for various reasons (Norwegian Directorate of Health, 2021). The new guidelines for services for Norwegian people with intellectual disability state that the cooperation of health follow-up between service users, GPs, and other service providers shall be documented in the service users' medical records and implemented in their IP (Norwegian Directorate of Health, 2021).

Strengths and limitations

This study has some limitations regarding representativeness. The sample is limited, and there may be selection bias as the included individuals were identified because they received health or care services; therefore, the results may not extend to other individuals with intellectual disability. Furthermore, representative analyses showed that the participants were significantly younger than the eligible non-participants, which may lead to underestimations of the use of services. Younger participants than non-participants would likely imply more healthy participants. As the use of healthcare services in participants increased with age, the older non-participants are overall likely to receive more health checks and have greater contact with their GPs than the participants. However, annual health checks are recommended in all adults; in the UK, this is applicable from age 14 (Public Health England, 2017). Another possible limitation of our study is that the P15 registers the use of services but not management of diseases. Ratings of healthcare services and dental health were

reported both by participants and proxies (family members or staff) at a single point in time but not verified in medical journals or service registries; this may be done in future studies. The use of proxy respondents in subjective matters like pain is not ideal, but in some cases, it is the only way. Proxy respondents have also been used in other studies (Kinnear et al., 2018). Scott and Haverkamp (2018) found satisfying correlations between self- and caregiver-reported health in individuals with intellectual disability. We did not adjust for multiple testing, risking Type 1 errors. However, numbers and percentages are always provided to the readers, and significant differences are discussed. A strength of this study is that the level of intellectual disability was confirmed in the participants' medical records.

Conclusions

Individuals with severe/profound intellectual disability underwent fewer health checks and visited their GPs less frequently than those with milder intellectual disability levels despite having, more often, physical health conditions requiring follow-ups (Folch et al., 2019). Access to adequate healthcare services for adults with intellectual disability needs to be enhanced, particularly cancer screening for women and annual comprehensive health assessments for individuals with more severe intellectual disability levels. Dental care services should be improved with concrete and evidence-based actions for individuals who have oral problems. As IPs to organise and coordinate services do not work as intended, this statutory right should be reconsidered.

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