

Health profiles in people with intellectual developmental disorders

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Folch-Mas A, Cortés-Ruiz MJ, Calderón PV, Martínez-Leal R.
Health profiles in people with intellectual developmental disorders.
Salud Publica Mex 2017;59:400-407.
<https://doi.org/10.21149/8199>

Folch-Mas A, Cortés-Ruiz MJ, Calderón PV, Martínez-Leal R.
Perfiles de salud en personas con trastornos del desarrollo intelectual.
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<https://doi.org/10.21149/8199>

Abstract

Objective. To better understand the health profiles of people with intellectual disability (ID), focusing on the variables that are associated with a poorer health status. **Materials and methods.** Data were collected from the Survey on Disability, Personal Autonomy and Dependency (EDAD 2008) of the Spanish National Statistics Institute (INE). The health data of 2 840 subjects with IDD were analyzed in order to verify the impact of different variables on their health profiles. **Results.** People with severe and profound levels of IDD presented a higher number of medical diagnoses. At residence centers there was a larger proportion of individuals with a higher prevalence of chronic diseases and more severe conditions; age also was an important factor. **Conclusion.** The health profiles of individuals with IDD differ depending on the severity level of their IDD and their degree of institutionalization. Further research is needed to provide better health care for people with IDD.

Keywords: intellectual disability; mental retardation; health profile; morbidity; aging

Resumen

Objetivo. Conocer los perfiles de salud de las personas con discapacidad intelectual (DI), incidiendo en las variables que se relacionan con un peor estado de salud. **Material y métodos.** Se han empleado datos procedentes de la Encuesta sobre Discapacidades, Autonomía personal y situaciones de Dependencia (EDAD 2008) del Instituto Nacional de Estadística (INE). Se han comparado los datos de salud de 2 840 sujetos con discapacidad intelectual para analizar las diferencias en sus perfiles de salud. **Resultados.** En los centros residenciales hay una mayor proporción de personas con DI profunda y severa, de edad más avanzada y con mayor prevalencia de enfermedades crónicas. Las personas con niveles más graves de DI presentan un mayor número de diagnósticos de enfermedades. **Conclusión.** Los perfiles de salud de las personas con DI difieren en función de su grado de institucionalización y su nivel de DI. Es necesario seguir investigando para ofrecer una mejor atención sanitaria a las personas con DI.

Palabras clave: discapacidad intelectual; retraso mental; perfil de salud; morbilidad; envejecimiento

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Received on: September 13, 2016 • **Accepted on:** May 12, 2017

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Mounting evidence suggests that individuals with Intellectual Developmental Disorders (IDD) have different health needs than the general population.¹⁻⁵ They also point out to a greater number of inequities suffered by this collective, such as a higher prevalence of adverse medical conditions and a lack of proper attention to their health needs.^{3,6-12}

Thus, people with IDD have health needs that are often unrecognized and untreated due to such factors as difficulties in communication, diagnostic overshadowing, discrimination, ignorance, or indifference.¹³ Generally, they suffer from more medical issues and have different morbidity patterns, and frequently these conditions are related to the cause of their disability. The lack of economic and social resources is often an added difficulty that accentuates health disparities.¹⁴ The effect of these disparities results in a significant reduction of the life expectancy and a mortality rate three times higher than those of the general population.^{7,8,15-17}

Recent literature has identified the main health issues faced by this population: they tend to suffer from more chronic diseases and to have larger number of multimorbidity patterns (having two or more chronic conditions), which often coexist with mental health problems and neurological disorders, concomitant medical issues, and comorbid challenging behavior.^{16,18,19}

Specifically, many studies have found higher risk and prevalence rates for diseases such as epilepsy, diabetes, chronic constipation, AIDS and sexually transmitted diseases, gastroesophageal reflux disease, dementia, gastrointestinal cancer, thyroid disease, osteoporosis, allergies, cerebral palsy, various genetic syndromes and genitourinary system diseases, among other conditions.^{8,20,21}

Moreover, multimorbidity has been positively associated with age, with the severity of the IDD and with the presence of Down's syndrome.²² Persons with severe and profound levels of IDD have a higher overall risk of developing health problems and medical complications, as well as a high prevalence of sensory impairments, and most of them require long-term pharmacological treatments.²³⁻²⁵ As they age, the risk of health problems increases and their life expectancy drops as the severity of the intellectual disability increases.^{26,27} Similarly, subjects with more severe levels of IDD often dwell at residence institutions and have a higher risk of diseases like epilepsy, mobility issues, mental health problems and behaviour disorders.²⁸

Besides presenting more severe levels of IDD, mental health issues and behaviour disorders, the population living in institutions has a higher mean age than their peers living in family households, and often leads a more sedentary life.^{26,29}

All these studies reflect the influence of variables like the severity of the IDD, ageing and institutionalization on the health status. This paper analyses the data from the survey EDAD 2008 carried out in order to understand the relationship of these variables with health profiles of people with IDD living in Spain. It also includes an analysis of the self-perceived health status of the participants, as self-rated health is a good indicator of the health status in population studies. However, it is important to note that research on self-rated health among this population is very scarce, given the limitations for the collection of information on individuals with severe levels of disability.^{15,30}

Materials and methods

We used data from the Survey on Disability, Personal Autonomy and Dependency (EDAD 2008) of the Spanish National Statistics Institute (INE). It is a macro-survey designed with the main purpose of providing a statistical basis for the phenomena of disability, dependency, aging, and health status of the Spanish population. It includes sociodemographic data and information on the health of the participants, collected during the years 2007 and 2008.

Sample

The EDAD 2008 survey involved 33 308 people who had some kind of disability, understanding this term as any important limitation to carry out everyday activities that has lasted or is expected to last more than one year and is caused by an impairment, such as the abnormality or loss of an organ function.

Out of the total sample, we selected those participants who had IDD, in order to analyze their health data. The resulting final sample consisted of 2 840 subjects with different levels of IDD.

Instruments and procedures

The EDAD 2008 survey was conducted in two stages: first, EDAD-Households (targeting family dwelling places) was administered to 96 000 homes/260 000 individuals between November 2007 and February 2008. The second stage, EDAD-Centres, was carried out between May and July 2008 at centres for disabled persons, psychiatric hospitals, and geriatric nursing homes and hospitals, involving 800 centres/11 000 individuals.

The data collected from the EDAD 2008 survey used in this study includes personal interviews consisting of various questionnaires, supplemented in some cases by telephone interviews. The Household Questionnaire,

Disability Questionnaire, Limitation Questionnaire and Main Carer Questionnaire were used in households. For the interviews with individuals living at residence centers, three types of questionnaires were administered: Center Questionnaire, Hospital Questionnaire and Person Questionnaire. Home and center questionnaires shared some common items, but also had items adapted to the specificities of each type of residence place. All questionnaires are available on the Spanish National Statistics Institute's website.*

Full details of the EDAD 2008 survey's development and methodology have been published in a public document provided by the INE^{31,32} and also within previous studies.^{33,34} The research was conducted in accordance with the Helsinki Declaration and revised by the Ethics Committee of the Ministry of Labor and Social Affairs, IMSERSO, the *Directorate-General for the Coordination of Sectoral Policies on Disability*, the ONCE Foundation, INE, CERMI and FEAPS.

Variables

All information collected in the EDAD 2008 survey was categorized into 855 variables, out of which we have selected those that are particularly relevant to the subject of this article, and which are common to both phases of the study: homes and residence centers.

We included sociodemographic variables such as age, sex, and participant's type of residence (home or center). For the participant's health profiles we used the following variables: severity of intellectual disability (Profound/Severe, Moderate, Mild, and Borderline Intellectual Functioning); presence of chronic diseases, defined as a long-term complaint that is not due to acute isolated processes, and diagnosis of diseases with medical certification. These variables refer to those diseases that have been diagnosed by medical personnel, and include: "Spinal cord injury, Parkinson, amyotrophic lateral sclerosis, multiple sclerosis, agenesis/amputations, laryngectomy, arthritis/osteoarthritis, rheumatoid arthritis/spondylitis, muscular dystrophy, spina bifida/hydrocephalus, infarction/ischemic cardiopathology, stroke, Down's syndrome, autism and related disorders, cerebral palsy, acquired brain damage, Alzheimer's disease, other dementias, schizophrenia, depression, bipolar disorder, pigmentary retinopathy, high myopia, age-related macular degeneration, diabetic retinopathy, glaucoma, cataracts, HIV / AIDS, rare diseases, and kidney failure".

Additionally, the study includes the subjective perception of the participant's own health status, through the variable "self-rated health", classified according to five levels: "very good, good, fair, poor, very poor, and the alternative option "decline to answer / do not know".

Statistical analysis

Descriptive analysis, Pearson's chi-squared tests and Student's t-tests were used for comparison of dichotomic and continuous variables (sex, age, severity of IDD, presence of chronic diseases, diagnosis of diseases with medical certification, and self-reported health) between both groups (homes vs. residences).

All statistical analyses were performed using SPSS statistics 19.0 for Windows, and the significance level was considered at $p < 0.05$.

Results

The total sample consisted of 2 840 subjects with IDD divided into two groups according to their living arrangements: homes ($n=833$) or institutional residences ($n=2\ 007$). Thus, 29.3% of the sample came from private households and 70.7% came from residential homes. Of the total sample, 55.6% were men and 44.4% were women. The total mean age was 44.45 years, with a standard deviation of 17.23 years and a range of ages between 6 and 96 years. Regarding IDD severity, 44.6% of the sample had severe and profound IDD (I.Q. between 0 and 34), 36% had moderate IDD (I.Q. between 35 and 49), 15.2% had mild IDD (I.Q. between 50 and 69), and 4.3% had a borderline intellectual functioning (I.Q. between 70 and 85). Results regarding sociodemographic variables, IDD severity level, and presence of chronic diseases are shown in table I.

There were no significant sex-related differences between home and the residential samples ($\chi^2=0.380$; $p=0.538$). Individuals living in residential settings were significantly older ($=47.26$ years) than those living in households ($=37.69$ years), ($t=-12.902$ (1328.463); $p < 0.001$). There were significant differences in the IDD severity level according to the type of dwelling; in residences there was a greater proportion of people with profound and severe IDD ($\chi^2=41.117$; $p < 0.001$) than in family households, where there was a higher number of individuals with mild IDD ($\chi^2=8.637$; $p=0.003$) or borderline intellectual functioning levels ($\chi^2=73.640$; $p < 0.001$). No statistically significant differences were found between homes and residence settings in regard to the number of individuals with Moderate IDD levels ($\chi^2=0.670$; $p=0.413$). Finally, a significantly higher prevalence of chronic diseases ($\chi^2=35.395$; $p < 0.001$) appeared in the residence sample.

* <http://www.ine.es/daco/daco42/discapa/cues07.htm>

Table I
SOCIODEMOGRAPHIC VARIABLES, INTELLECTUAL DISABILITY LEVEL AND PRESENCE OF CHRONIC DISEASES.
COMPARISONS BETWEEN COMMUNITY AND RESIDENCE SETTINGS. REUS, 2014

Variables	Homes (n=833)	Residences (n=2 007)	Total (n=2 840)	SIG
Sex (male/female)	456/377 54.7%/45.3%	1 124/883 56.0%/44.0%	1 580/1260 55.6%/44.4%	$\chi^2=0.380$; $p=0.538$
Mean age \pm SD	37.69 \pm 18.902 (Range 6-92)	47.26 \pm 15.654 (Range 8-96)	44.45 \pm 17.23 (Range 6-96)	$t=-12.902$ (1328.463); $p<0.001^*$
Profound and severe IDD	294 (35.3%)	972 (48.4%)	1266 (44.6%)	$\chi^2=41.117$; $p<0.001^*$
Moderate IDD	309 (37.1%)	712 (35.5%)	1021 (36.0%)	$\chi^2=0.670$; $p=0.413$
Mild IDD	152 (18.2%)	279 (13.9%)	431 (15.2%)	$\chi^2=8.637$; $p=0.003^*$
Borderline IF	78 (9.4%)	44 (2.2%)	122 (4.3%)	$\chi^2=73.640$; $p<0.001^*$
Chronic diseases	460 (55.2%)	1271 (63.3%)	1731 (61%)	$\chi^2=35.395$; $p<0.001^*$

* $p<0.05$

SD: standard deviation

IDD: Intellectual developmental disorders

IF: intellectual functioning

Table II shows the statistically significant results for disease diagnosis, dividing the data into four levels of IDD and providing a comparison between family homes and residence centers.

According to the results, people with more severe levels of IDD had a higher number of diagnoses of diseases than those with mild or borderline IDD levels.

More specifically, an increased prevalence of other dementias (non-Alzheimer dementias) was found ($\chi^2=3.970$; $p=0.046$) in the group of subjects with severe and profound IDD living in residential settings. In contrast, results of individuals with severe and profound IDD living in family households showed a higher prevalence of health problems such as arthritis/osteoarthritis ($\chi^2=26.217$; $p<0.001$), rheumatoid arthritis/spondylitis ($\chi^2=12.824$; $p<0.001$), muscular dystrophy ($\chi^2=12.728$; $p<0.001$), Infarction / Ischemic cardiopathology ($\chi^2=16.611$; $p<0.001$), stroke ($\chi^2=47.780$; $p<0.001$), Down's syndrome ($\chi^2=92.283$; $p<0.001$), cerebral palsy ($\chi^2=5.530$; $p=0.019$), acquired brain damage ($\chi^2=16.652$; $p<0.001$), depression ($\chi^2=47.869$; $p<0.001$), high myopia ($\chi^2=28.679$; $p<0.001$), rare diseases ($\chi^2=10.987$; $p<0.001$) and kidney failure ($\chi^2=11.515$; $p<0.001$).

In the group of subjects with moderate IDD living in residence centers, there were significant differences in the diagnosis of schizophrenia compared to those in households ($\chi^2=11.095$; $p<0.001$). As before, the results in family households showed a higher prevalence of health problems such as spinal cord injury ($\chi^2=5.701$; $p=0.017$), laryngectomy ($\chi^2=9.253$; $p=0.002$), arthritis /

osteoarthritis ($\chi^2=7.127$; $p=0.008$), rheumatoid arthritis/spondylitis ($\chi^2=15.695$; $p<0.001$), spina bifida/hydrocephalus ($\chi^2=11.578$; $p<0.001$), Down's syndrome ($\chi^2=19.218$; $p<0.001$), cerebral palsy ($\chi^2=11.361$; $p<0.001$), acquired brain damage ($\chi^2=18.880$; $p<0.001$), depression ($\chi^2=17.462$; $p<0.001$), and high myopia ($\chi^2=5.737$; $p=0.017$).

When comparing individuals with mild IDD levels living in residences or in family homes, we found that the diagnosis of schizophrenia was more frequent in residences. However people with mild IDD living in family homes presented more frequently diagnosis of arthritis/osteoarthritis ($\chi^2=5.923$; $p=0.015$), rheumatoid arthritis/spondylitis ($\chi^2=17.199$; $p<0.001$), strokes ($\chi^2=11.491$; $p<0.001$), Down's syndrome ($\chi^2=17.919$; $p<0.001$) and rare diseases ($\chi^2=16.872$; $p<0.001$). In general people with mild IDD presented less medical diagnoses than people with more severe levels of IDD.

Finally, in the cases of borderline intellectual functioning, there was no representation of most of the illnesses. Statistically significant differences only appeared in centers, with a higher prevalence of mental illnesses such as other dementias (non-Alzheimer dementias) ($\chi^2=3.986$; $p=0.046$), schizophrenia ($\chi^2=7.331$; $p=0.007$) and bipolar disorder ($\chi^2=6.810$; $p=0.033$).

No significant differences between community and residence populations were appreciated among IDD levels in relation to the diagnosis of diseases such as Parkinson's, amyotrophic lateral sclerosis, multiple sclerosis, agenesis/amputations, autism and related disorders, Alzheimer's disease, pigmentary retinopathy,

Table II
SIGNIFICANT DIFFERENCES IN DISEASE DIAGNOSIS BY LEVEL OF INTELLECTUAL DISABILITY.
COMPARISONS BETWEEN COMMUNITY AND RESIDENTIAL SETTINGS. REUS, 2014

Level	Disease Diagnosis	Homes (n=294)	Residences (n=972)	Total (n=1 266)	SIG
Profound / Severe IDD	Arthritis/Osteoarthritis	31 (10.5%)	31 (3.2%)	62 (4.9%)	$\chi^2=26.217$; $p<0.001^*$
	Rheumatoid arthritis/Spondylitis	8 (2.7%)	4 (0.4%)	12 (0.9%)	$\chi^2=12.824$; $p<0.001^*$
	Muscular dystrophy	25 (8.5%)	34 (3.5%)	59 (4.7%)	$\chi^2=12.728$; $p<0.001^*$
	Infarction/Ischemic cardiopathology	20 (6.8%)	20 (2.1%)	40 (3.2%)	$\chi^2=16.611$; $p<0.001^*$
	Stroke	36 (12.2%)	24 (2.5%)	70 (4.7%)	$\chi^2=47.780$; $p<0.001^*$
	Down's syndrome	74 (25.2%)	56 (5.8%)	130 (10.3%)	$\chi^2=92.283$; $p<0.001^*$
	Cerebral palsy	51 (17.3%)	117 (12%)	168 (13.3%)	$\chi^2=5.530$; $p=0.019^*$
	Acquired brain damage	96 (32.7%)	205 (21.1%)	301 (23.8%)	$\chi^2=16.652$; $p<0.001^*$
	Other dementias	37 (12.6%)	170 (17.5%)	207 (16.4%)	$\chi^2=3.970$; $p=0.046^*$
	Depression	31 (10.5%)	17 (1.7%)	48 (3.8%)	$\chi^2=47.869$; $p<0.001^*$
	High myopia	17 (5.8%)	8 (0.8%)	25 (2%)	$\chi^2=28.679$; $p<0.001^*$
	Rare diseases	18 (6.1%)	22 (2.3%)	40 (3.2%)	$\chi^2=10.987$; $p<0.001^*$
	Kidney failure	9 (3.1%)	6 (0.6%)	15 (1.2%)	$\chi^2=11.515$; $p<0.001^*$
	Spinal cord injury	6 (1.9%)	3 (0.4%)	9 (0.9%)	$\chi^2=5.701$; $p=0.017^*$
Laryngectomy	4 (1.3%)	0 (0%)	4 (0.4%)	$\chi^2=9.253$; $p=0.002^*$	
Moderate IDD	Arthritis/Osteoarthritis	27 (8.7%)	32 (4.5%)	59 (5.8%)	$\chi^2=7.127$; $p=0.008^*$
	Rheumatoid arthritis / Spondylitis	11 (3.6%)	3 (0.4%)	14 (1.4%)	$\chi^2=15.695$; $p<0.001^*$
	Spina bifida / Hydrocephalus	5 (1.6%)	0 (0%)	5 (0.5%)	$\chi^2=11.578$; $p<0.001^*$
	Down's syndrome	92 (29.8%)	125 (17.6%)	217 (21.3%)	$\chi^2=19.218$; $p<0.001^*$
	Cerebral palsy	25 (8.1%)	23 (3.2%)	48 (4.7%)	$\chi^2=11.361$; $p<0.001^*$
	Acquired brain damage	77 (24.9%)	98 (13.8%)	175 (17.1%)	$\chi^2=18.880$; $p<0.001^*$
	Schizophrenia	3 (1.7%)	39 (4.3%)	42 (3.6%)	$\chi^2=11.095$; $p<0.001^*$
	Depression	33 (10.7%)	28 (3.9%)	61 (6%)	$\chi^2=17.462$; $p<0.001^*$
	High myopia	13 (4.2%)	12 (1.7%)	25 (2.4%)	$\chi^2=5.737$; $p=0.017^*$
	Arthritis/Osteoarthritis	14 (9.2%)	10 (3.6%)	24 (5.6%)	$\chi^2=5.923$; $p=0.015^*$
MildIDD	Rheumatoid arthritis / Spondylitis	11 (7.2%)	1 (0.4%)	12 (2.8%)	$\chi^2=17.199$; $p<0.001^*$
	Stroke	12 (7.9%)	4 (1.4%)	16 (3.7%)	$\chi^2=11.491$; $p<0.001^*$
	Down's syndrome	17 (11.2%)	5 (1.8%)	22 (5.1%)	$\chi^2=17.919$; $p<0.001^*$
	Schizophrenia	2 (1.7%)	18 (4.3%)	20 (3.6%)	$\chi^2=5.865$; $p=0.015^*$
	Rare diseases	9 (5.9%)	0 (0%)	9 (2.1%)	$\chi^2=16.872$; $p<0.001^*$
	Other dementias	4 (5.1%)	7 (15.9%)	11 (9%)	$\chi^2=3.986$; $p=0.046^*$
	Schizophrenia	0 (1.7%)	4 (4.3%)	4 (3.6%)	$\chi^2=7.331$; $p=0.007^*$
Borderline	Bipolar disorder	0 (0.6%)	2 (4.5%)	2 (1.6%)	$\chi^2=6.810$; $p=0.033^*$

* $p<0.05$

IDD: Intellectual developmental disorders

age-related macular degeneration, diabetic retinopathy, glaucoma, cataracts, and HIV / AIDS.

Last, table III lists the results of the interviewee's self-reported health status.

There were no significant statistical differences for the self-perception of health as very good ($\chi^2=1.017$; $p=0.313$), poor ($\chi^2=3.093$; $p=0.079$) or very bad ($\chi^2=1.840$; $p=0.175$). Also, there were no apparent differences for

the option "decline to answer / do not know" ($\chi^2=2.182$; $p<0.140$).

However, among interviewees living in centers, significant differences were found when the own health status was rated as good ($\chi^2=12.524$; $p<0.001$), whereas most of those living in households perceived their own health as fair ($\chi^2=10.510$; $p<0.001$).

Table III
SELF-RATED HEALTH. COMPARISONS BETWEEN COMMUNITY AND RESIDENTIAL SETTINGS. REUS, 2014

Self-rated health	Homes (n=833)	Residences (n=2 007)	Total (n=2 840)	SIG
Very good	46 (5.5%)	131 (6.5%)	177 (6.2%)	$\chi^2=1.017$; $p=0.313$
Good	441 (52.9%)	1 207 (60.1%)	1 648 (58%)	$\chi^2=12.524$; $p<0.001$ *
Fair	242 (29.1%)	467 (23.3%)	709 (25%)	$\chi^2=10.510$; $p<0.001$ *
Bad	81 (9.7%)	155 (7.7%)	236 (8.3%)	$\chi^2=3.093$; $p=0.079$
Very bad	22 (2.6%)	37 (1.8%)	59 (2.1%)	$\chi^2=1.840$; $p=0.175$
Decline to answer/ do not know	1 (0.1%)	10 (0.5%)	11 (0.4%)	$\chi^2=2.182$; $p=0.140$

* $p<0.05$

Discussion

According to the results found, the health profiles of people with IDD differ depending on their degree of institutionalization. In residential centers we found a higher proportion of individuals with profound and severe IDD, with a higher mean age and a greater prevalence of chronic diseases compared to those in family households. Thus, mild and borderline IDD levels were more prevalent among people living in family households; there were younger and the prevalence of chronic diseases is significantly lower among them.

From the data, it can be extrapolated that individuals with more severe levels of IDD have a higher number of diagnoses of diseases than those having mild and borderline IDD levels. People living in centers often have more mental illnesses such as schizophrenia, bipolar disorder and other types of dementias (non-Alzheimer dementias), while the diseases afflicting family household dwellers are more physical illnesses. Although center participants are affected by higher degrees of IDD severity, they seem to have fewer illnesses than their peers in households.

With regard to the assessment of their own health, the data suggest that a good self-rated health prevails at residences, while a fair self-rated health prevails at family homes.

Comparison with other studies

Previous research, findings are consistent with the results presented here: residence patients are significantly older than those living in community settings,^{26,28,29} are affected by more severe levels of IDD²⁸ and are more likely to suffer from mental health problems and behavioral disorders.^{28,29} In this sense, recent literature shows that people with IDD have a higher risk of developing comorbid psychopathology, and their symptoms remain relatively stable over time.^{35,36} It is estimated

that approximately one third of the population with IDD suffers comorbid psychopathology, and although most studies find higher rates of mental disorders among populations with mild to moderate IDD, it appears that these differences are due to the difficulties in the diagnosis among people with more severe levels of IDD.^{37,38} Consistently, in the present study, individuals with milder levels of IDD exhibited almost exclusively comorbid diagnoses of mental illness, and similarly, residents at centers have also shown a higher prevalence of these diseases at all IDD levels. In regard to dementia, the results show a significant impact on the residence population, mainly in subjects with profound / moderate and borderline IDD levels. This fact makes even more sense if we consider that the population at centers has a higher mean age, since the incidence of dementia in older people with IDD is up to five times higher than among the general population.³⁹⁻⁴¹

Subjects residing in family homes have a higher number of diseases diagnosed with medical certification. Although much of the literature associates the fact of living in a residence with more severe levels of IDD, and therefore, with a greater comorbidity of medical illnesses, it is also true that, according to previous studies, significant deficits on measures to promote healthcare—such as vaccinations, preventive healthcare and medical checkups—among the community population have been identified which might compromise the health of these people.^{8,42} Accordingly, it is likely that people living in institutions have a better access to health care measures so more research is needed to develop a better understanding of this matter. It would also be necessary to verify that this is not a diagnostic overshadowing effect in centers, since individuals with higher degrees of severity may be suffering undiagnosed and untreated illnesses due to the difficulties associated with the communication and expression of their symptoms.¹³

The measures of self-rated health may shed light on this subject: according to the data obtained from

participants who live at family homes, these have a poorer self-rated health, even though there are individuals with more severe levels of IDD living in residences. It seems that these evaluations support the results obtained, although, since they are subjective perceptions, and considering the difficulties in making this assessment due to the disability itself, they should be interpreted with caution as a preliminary result. However, this is an open way to new avenues of research in which the views of the participants are taken into account.^{40,41,43}

Limitations and future research proposal

The data used in this article were obtained from the Survey on Disability, Personal Autonomy and Dependency (EDAD 2008). The fact that we did not participate directly in the data collection means that there may be errors or methodological problems beyond our control. Moreover, since the surveys were conducted in 2008, the data may fail to conform to current social and demographic conditions. The questionnaires were answered subjectively by participants or substitute informants, so the reliability of the data collected may be compromised. Finally, although the size of the sample is large (n=2 840), it includes few participants with borderline intellectual functioning (n=122), and therefore it is difficult to generalize the results to the total population with borderline intellectual functioning in Spain, so these findings should be considered with caution. Anyway, this study provides initial results that can contribute to the research of the health status of individuals with IDD in the Spanish state and highlights the need for further high-quality epidemiological studies addressing a larger sample size.

Proposal for practical applications

More research on this topic needs to be undertaken in order to allow reaching a consensus on such a rapidly developing field, which may help provide better care to individuals with IDD. This requires an evolution of public health policies as well as an adaptation of primary healthcare services through the development of specialized preventive services and the creation of new specialized services. A proactive healthcare, with specific protocols, guidelines, and training programs for health professionals is needed.

The implementation of regulatory programs and inspections to ensure that individuals with IDD are not discriminated against and that they receive quality healthcare is imperative. Similarly, it is essential to implement health surveys and epidemiological stud-

ies including specific data on this population and to optimize our knowledge of their needs. The overall prevalence of IDD is approximately 1%, and the highest rates are found in lower-income countries, where the resources for its management are limited.⁴⁴ Therefore, it is essential to know the health profiles of this population in order to improve their life quality and minimize the related health costs, which currently represent a significant proportion of health expense in Western Europe.⁴⁵

Declaration of conflict of interests. The authors declare that they have no conflict of interests.

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