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The Change in the Epidemiology of Intellectual Disability in Spain: 1999-2008

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Abstract

Introduction: Few studies exist in Spain that explore the possible changes in the intellectual disability epidemiology over large periods of time. This study delves into what changes have occurred between the years 1999 and 2008, and the possible reasons behind these differences. The main objective of this study is to describe, analyze, and compare the epidemiological data on intellectual disability in Spain from two separate but similar national polls taken during each of these years.

Methods and Materials: This study was descriptive, observational, cross-sectional, and analyzed retrospectively. The data used were obtained from the microdata archives of the Disabilities, Deficits, and Health State survey (Encuesta nacional de Discapacidades, Deficiencias y Estados de Salud) completed by the Instituto Nacional de Estadística (INE) in 1999. The microdata archives were transformed utilizing syntax archives and the descriptive analysis was executed with SPSS. Afterwards, statistical analysis was done to compare the data obtained from the 1999 survey to the data obtained from the 2008 survey.

Results: Including the ID population from the institutions surveyed in 2008, the relationship between the two variables was significant, X^2 (1, N=218,185) = 10.25, p<.01. The prevalence of ID in 1999 (0.39%) was lower than in 2008 (0.44%). Excluding the data collected from the institutions in 2008 again gave a significant difference between the two years, X^2 (1, N=218,185) = 7.29, p<.01. In this case, however, the prevalence of ID in 1999 (0.39%) was significantly higher than in 2008 (0.36%). The change in the prevalence of Down syndrome between the two years was not significant, X^2 (1, N=981) =0.021, p=0.88.

Conclusions: Since institutions were not polled in the 1999 survey, conclusions were drawn based on the data gathered from residential housing only. Statistical analysis shows a significant decrease in the prevalence of ID from 1999 to 2008, which could be caused by two main factors: a decrease in the live birth of children with Down syndrome and the large influx of non-disabled immigrants between the ages of 20 and 50 who have entered Spain to either study or work over this period. As a large number of different databases both within Spain and without have shown a steady increase in the prevalence of ID and disability in general, further comparisons should be done which analyze the changes present in ID prevalence—including data retrieved from institutions, which represent an important percentage of the ID population—between 2008 and the present.

Keywords: Intellectual Disability, Down Syndrome, Spain, Epidemiology

Resumen

Introducción: En España hay pocos estudios sobre los posibles cambios de la epidemiología de la discapacidad intelectual durante largos periodos de tiempo. Este estudio explora los cambios que han ocurrido entre los años 1999 y 2008, y las posibles razones de estas diferencias. El objetivo principal de este estudio es describir, analizar y comparar los datos epidemiológicos de la discapacidad intelectual en España de estas dos encuestas nacionales.

Materiales y Métodos: Estudio descriptivo, observacional, de corte transversal y carácter retrospectivo. Los datos fueron obtenidos a partir de los archivos de microdatos de la Encuesta nacional sobre Discapacidades, Deficiencias y Estados de Salud realizada por el Instituto Nacional de Estadística (INE) en España 1999. Los archivos de microdatos fueron transformados utilizando los archivos de sintaxis y el análisis descriptivo fue ejecutado a través de SPSS. Después, se realizó un análisis estadístico para comparar los datos que fueron obtenidos de la encuesta de 1999 y la encuesta de 2008.

Resultados: Incluyendo la población de DI de las instituciones encuestadas en 2008, la relación entre los variables fue significante, X^2 (1, N=218,185) = 10.25, p<.01. La prevalencia de DI en 1999 (0.39%) fue más bajo que en el 2008 (0.44%). Excluyendo los datos recolectados de las instituciones en 2008 otra vez dio una diferencia significativa entre los dos años, X^2 (1, N=218,185) = 7.29, p<.01. Sin embargo, la prevalencia de DI en 1999 (0.39%) fue más alta que en el 2008 (0.36%). Los cambios en la prevalencia de síndrome de Down entre los dos años no fue significante, X^2 (1, N=981)= 0.021, p=0.88.

Conclusiones: Debido a que las instituciones no fueron encuestadas en la encuesta de 1999, las conclusiones de este estudio estuvieron basadas solo en los datos de las viviendas familiares. El análisis estadístico demuestra una disminución significativa en la prevalencia de la DI de 1999 a 2008, que podría ser causado por dos factores principales: una disminución de los nacimientos de niños con síndrome de Down y la entrada de inmigrantes sin discapacidades entre los 20-50 años quienes han entrado a España para trabajar o estudiar durante este tiempo. Debido al gran número de bases de datos en España y en otros países que han demostrado un aumento de la prevalencia de DI y discapacidades en general, más comparaciones deben hacerse para analizar los cambios presentes en la prevalencia de DI—incluyendo los datos de las instituciones, los cuales representan un porcentaje de la población de DI importante—entre 2008 y el presente.

Palabras Claves: Discapacidad Intelectual, Síndrome de Down, España, Epidemiología

Introduction

Few studies exist in Spain that explore the possible changes in the intellectual disability (ID) epidemiology over large periods of time. This study delves into what changes have occurred between the years 1999 and 2008 and, if significant changes in epidemiology are observed, the possible reasons behind these differences. One of the main objectives of this study is to describe, analyze, and compare the epidemiological data on intellectual disability in Spain from two separate but similar national polls taken during each of these years.

This work expands upon the research done by Josep Pascual Bardají, Diana Milena Gutiérrez Peña, Jordi Casas Sánchez, and Marian March (2016) on the intellectual disability epidemiology in Spain in 2008, and uses it as a basis of comparison for the 1999 results analyzed in this work. Their article analyzed data from the nationwide survey, Disabilities, Personal Autonomy, and Situations of Dependence (Encuesta nacional de Discapacidades, Autonomía personal y situaciones de Dependencia) performed in 2008. The results obtained from this survey show that the estimated prevalence of intellectual disability was 0.44%, while the prevalence of Down syndrome within the intellectual disability community was 18.7%. People with intellectual disabilities were found to have other, non-related deficits at a rate of 23.57%. Additionally, the sex ratio showed a much higher prevalence of intellectual disability in men. As noted in the paper, it is important to know the magnitude of intellectual disability at both national and local levels in order to make government decisions based on real information. For example, it is useful to take real, current data into account when creating programs to promote the development, education, interests, and well-being of people with intellectual disability. (Bardají, 2016)

The Disabilities, Personal Autonomy, and Situations of Dependence survey of 2008 was modeled after the Disabilities, Deficits, and Health State survey (Encuesta nacional de Discapacidades, deficiencias y estados de salud) completed in 1999 at a national level. One of the main objectives of the 1999 survey was to estimate the total number of people living in family housing who suffered from some sort of disability, and to have a better idea of which types of disabilities were the most prevalent. This information was collected with the intention of permitting us to quantify the number of people with disabilities whose activities were limited. A second objective was to identify

the distinct types of deficits that resulted in disabilities, and to study the causes that produced these deficits. Knowing the origin of a disability makes it easier to develop and expand upon both preventative programs and social policies aimed at reducing these deficits in the future. Another goal of this survey was to evaluate possible difficulties in the Spanish social environment that people with disabilities regularly face. Examples of such difficulties include any disadvantage suffered as a consequence of a disability that is related to the work field or to the normal education process. For the purpose of this study, most of the information extracted and analyzed from the 1999 Disabilities, Deficits, and Health State survey and the 2008 Disabilities, Personal Autonomy, and Situations of Dependence survey will focus on the intellectual disability population; nevertheless, some statistics surrounding the disabled population in general will be included for supporting evidence and a more extensive understanding of the obstacles the community encounters as a whole.

According to registered data from the different Autonomous Communities in Spain, there were 234,915 people with recognized intellectual disabilities at the end of 2013. As the recorded population of Spain at the end of 2013 was 46,507,760, the prevalence of intellectual disability was 0.50%. Within this population, 57% were male (134,127) and 43.5% were female (100,788). Separated into age groups, 16.5% of the ID population were between the ages of 0 and 17, 29% were between 18 and 34 years, 46% were between 35 and 64 years, 6.5% were between 65 and 79 years, and 1.6% were over the age of 80. While the data collected by the public administrations work as a good estimate of the prevalence of ID in Spain, the numbers are not completely accurate as they only reflect the number of people who possess an official certificate of disability. The following statistic is an example of the possible unreliability of these numbers as an accurate estimation of the prevalence of ID in Spain: it has been calculated that 70% of the people who enter prison with an intellectual disability do so without previous recognition of the disability. With this said, it is possible that there are other cases of ID that are unknown to the registrar. (La discapacidad intelectual en cifras, 2016)

Another database that can be used to corroborate the information obtained from the national surveys conducted in 1999 and 2008 is the National Database of People with Disability (Base de datos Estatal de Personas con Discapacidad). This database is a

general register of every person in Spain who has been granted the legal status of handicap. In December of 2015, the database showed that 8.96% of the registered disabilities in Spain were intellectual. Since the total number of disabilities registered was 2,998,639, there were 268,678 registered cases of ID. As the recorded general population of Spain in 2015 was 46,423,064, the prevalence of ID is estimated at 0.57%. (Inserso, 2016)

When comparing the data from both the surveys and the national databases, it appears as though the prevalence of intellectual disability in Spain has been steadily increasing since 1999. This study aims to use statistical analysis to compare the data from 1999 and 2008 to determine if this change in prevalence is statistically significant. Additionally, this study delves into what intellectual disability entails, a few of the most well-known intellectual disabilities, a history of the diagnostic procedure, and the social integration problem that many people with disabilities face on a daily basis.

Intellectual disability

The term intellectual disability (ID) is normally used when referring to a person who possesses certain limitations in both cognitive functioning and other skills. According to the American Association on Intellectual and Developmental Disabilities, intellectual disability is "a disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills, and originates before the age of 18" (AAIDD, 2010). ID is a developmental disability which often causes a child to learn and develop at a slower rate than most other children. While many intellectual disabilities are consequences of genetic abnormalities, an ID can occur at any time before a child turns 18. The most common causes of ID are injury, disease, or problems in the brain; however, there are many cases of ID in which the cause is unknown. Some examples of common causes of ID are Down syndrome, Fetal Alcohol syndrome, Fragile X syndrome, Autism, Phenylketonuria, and birth defects. From a combination of multiple international surveys and studies, it is estimated that approximately 1-3 percent of the global population has an intellectual disability; however, this prevalence is significantly higher in low-income countries. For example, it is estimated that 6.5 million people living in the United States had an intellectual disability in 2016, or approximately 2 percent of the population. (What is Intellectual Disability)

Down Syndrome. One of the leading genetic causes of developmental disabilities and birth defects are aneuploidies emanating early in the developmental phase (Chiang, 2010). An aneuploidy is a cell with an abnormal number of chromosomes present. Since the normal number of chromosomes in a cell is 46, any cell that has 45 or 47 chromosomes would be considered an aneuploidy. One of the most famous aneuploidies is Down syndrome, or trisomy 21. Down syndrome occurs when there is an extra copy of chromosome 21 in the cell. While an abnormality can occur at any of the 23 chromosomes during the meiosis process, Down syndrome is the most well-known because it is one of the only trisomies which does not result in miscarriage or pre-mature death. The easily identifiable physical features of Down syndrome also aid in the disorder's universal recognition. Some of the common physical symptoms of Down syndrome include decreased or poor muscle tone, a short neck, a flattened facial profile and nose, and upward slanting eyes with a skin fold that comes out from the upper eyelid and covers the inner corner of the eye. Additional physical symptoms include wide, short hands and a small head, ears, and mouth. Physical development of children with Down syndrome may also be slower than that of normal children; however, most children with Down syndrome are eventually able to participate in physical exercise activities just like normally developing children. Some of the common intellectual and developmental symptoms of Down syndrome include cognitive impairments, problems with thinking and learning, a short attention span, impulsive behavior, and delayed language and speech development. In addition to the previously mentioned symptoms, people with Down syndrome are at an increased risk for other health conditions, which must be monitored. (NIH)

Aneuploidies result from problems during meiosis: the process that creates four haploid progenies from one diploid parental cell. Cell division occurs in two phases: Meiosis I and Meiosis II. Meiosis I is initiated after the completion of S phase. Meiosis I begins with an extended prophase in which homologous chromosomes pair up and perform recombination by joining at cross over sites called chiasmata. After prophase is complete, metaphase I begins and the paired chromosomes are attached to the spindle through microtubules after aligning along the metaphase plate. The chiasmata are disrupted during anaphase I when microtubules separate the homologous chromosomes. At the end of anaphase I, sister chromatids remain attached at their centromeres, resulting

in two daughter cells that have each acquired one member of the homologous pair. Meiosis II is different from meiosis I as it more closely resembles the mitosis process. During metaphase II, chromosomes align at the spindle equator individually, not grouped into homologous pairs. Because of this, microtubules from opposite poles of the spindle attach to the kinetochores of sister chromatids instead, breaking their centromeres during anaphase II and ending in the creation of two haploid daughter cells. Once the meiosis process has been completed in its entirety, one diploid parental cell has been transformed into four haploid daughter cells. (Cooper, 2000) This process is demonstrated below in Figure 1.

When it comes to oocyte meiosis, or oogenesis, the process faces some additional regulations. Specifically, the meiosis of human oocytes is regulated at two points during the cell cycle. The diplotene stage of meiosis I is the first point of regulation in oocyte meiosis. One notable characteristic of this stage of arrest is the immense growth of the primary oocyte due to active transcription and the accumulation of materials needed for early embryonic development. Hormonal stimulation resumes meiosis I, which results in the production of a large secondary oocyte and a small polar body. The oocyte is arrested again once it enters metaphase II, and it remains arrested in this stage until it has been

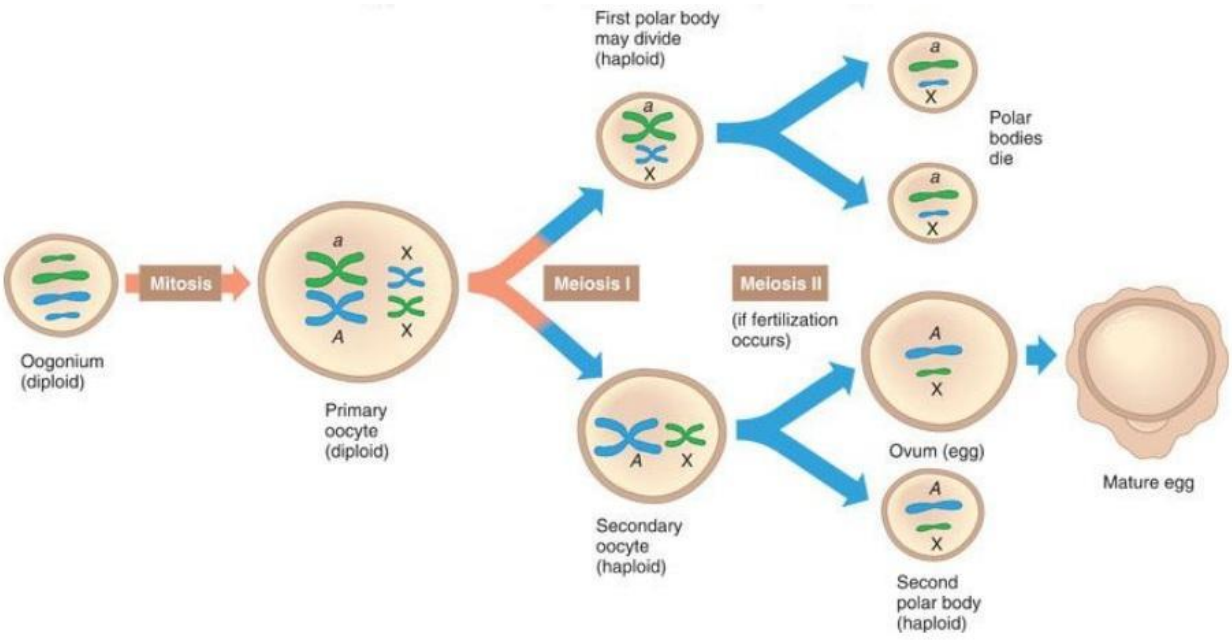
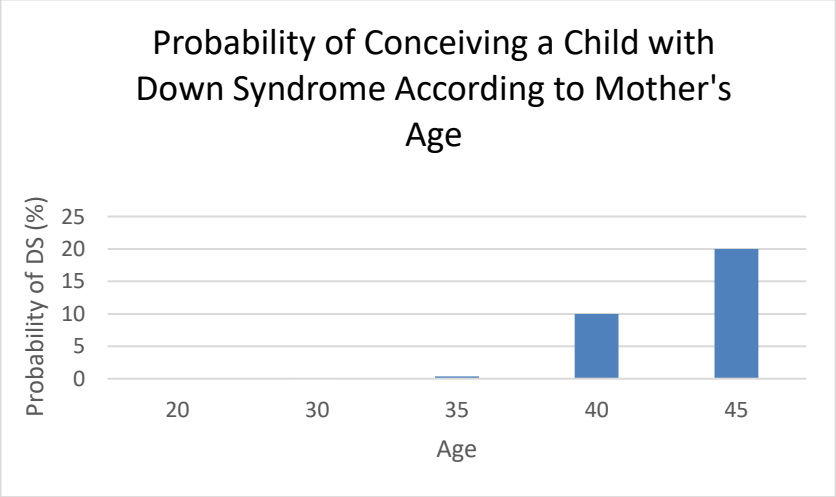


Figure 1. Pictorial representation of oogenesis (Stem Cells Thailand, 2013)

fertilized. At the end of oogenesis, the primary oocyte has been transformed into one ovum and two small polar bodies, as the first polar body normally dies before completing meiosis II.

It has been well documented that women over the age of 35 have a higher risk of giving birth to a child with Down syndrome. This risk continues to increase with age, as shown in Graph 1. Although the link between age and resulting aneuploidies is well known, the molecular causes of these chromosome separating errors are uncertain. Teresa Chiang, Francesca Duncan, Karen Schindler, Richard Schultz, and Michael Lampson (2010) explored the hypothesis that one of the leading causes of aneuploidy in older oocytes is weakened chromosome cohesion. One sign of weakened sister centromere cohesion is the disruption of the kinetochore structure, specifically the inter-kinetochore distance. A kinetochore is a multiprotein structure that forms at centromeres in order to attach chromosomes to spindle fibers. The outer layer of kinetochore proteins is responsible for both microtubule attachment and checkpoints that monitor several important aspects of kinetochore and spindle formation (Gerton, 2007). When analyzing their results, Chiang et al. concluded that sister kinetochores are farther apart at both metaphase I and II in older oocytes (Chiang, 2010). These findings were corroborated in a separate study done by Julie Lagirand-Cantaloube et al., which measured the mean inter-kinetochore distance in meiosis I oocytes. They found that the distance increased with age, as the average distance for women under the age of 30 was 0.73 ± 0.32 μm, while



Graph 1. Representation of the change in probability of conceiving a child with Down syndrome (DS) as the mother's age increases. (Down's syndrome)

the average distance for women over the age of 30 was $1.2 \pm 0.34\,\mu m$ (Lagirand-Cantaloube, 2017). As described before, the correct segregation of homologous chromosomes during meiosis I is dependent on monopolar attachment of sister chromatids—the attachment of both sister chromatids to the same spindle pole—and bipolar attachment of chromosome pairs. Sister centromere cohesion has proven to play an essential role in the monopolar attachment of sister chromatids during metaphase I (Yamamoto, 2003). Without proper cohesion, biorientation can occur. Bioriented chromatids are then pulled in opposite directions, which leads to the gain or loss of one single chromatid in the oocyte (Lagirand-Cantaloube, 2017). The analysis of unfertilized human metaphase II oocytes performed in the Chiang et al. study suggests that 90% of aneuploidies seen in old eggs are due to improper kinetochore biorientation or premature chromatid separation in metaphase I, both conditions caused by weakened centromere cohesion. The prevalence of unpaired chromatids in metaphase II is a strong indication that defects in centromere cohesion act as huge contributors to advanced maternal age aneuploidy. Additionally, is widely thought that loss of centromere cohesion could contribute to an increase in aneuploidies by promoting the disintegration of bivalents into univalents during metaphase I.

In a properly functioning cell, defects in kinetochore attachment lead to the activation of the spindle assembly checkpoint (SAC). SAC occurs during metaphase as a safeguard mechanism that prevents premature chromosome segregation before correct kinetochore-microtubule binding. In theory, the incorrect attachment of bivalents would only lead to aneuploidy if the oocyte were allowed to bypass checkpoints and progress to anaphase. For this reason, an important question to ask when hypothesizing about the causes of increased aneuploidy in advanced maternal ova is whether the spindle assembly checkpoint was active in these oocytes. The Lagirand-Cantaloube et al. study delves into this question by researching two important SAC proteins: BUB1 and BUBR1. They found that both proteins are localized at kinetochores with the same temporal pattern as in mitotic cells. In addition, they found that BUBR1 protein levels were constant in both older and younger human oocytes; nevertheless, they also observed that BUBR1 kinetochore localization significantly decreased with age. These findings suggest that the SAC mechanism may become less efficient as oocytes age. Research done on

mouse oocytes demonstrates similar results, and the loss of SAC components have been shown to lead to both the acceleration of meiosis I and severe chromosome missegregations. In mice, the reduction of kinetochore localization of MAD2, a SAC protein, has been found in aged oocytes. One reason for the incorrect delocalization of SAC proteins could be a result of increased inter-kinetochore distances of sister chromatids. The bipolar attachment of sister chromatids due to this increased distance might lead to the creation of a tension that "spatially separates aurora B/C from the inner centromere," stabilizing improper microtubule-kinetochore attachments. In this way, homologous chromosomes are incorrectly recognized as sister chromatids, and SAC is bypassed. While failure of the spindle assembly checkpoint is one of the leading hypotheses of advanced maternal age aneuploidy, there is still a lack of empirical evidence proving that defects in the spindle assembly checkpoint process lead to an increased number of aneuploidies.

Autism Spectrum Disorder. Autism Spectrum Disorder (ASD), or autism, is a complex neurological and developmental disorder that affects both the structure and function of the brain and the nervous system. While people with autism normally have difficulties with things such as communication, social skills, and behaviors, the symptoms of each person who suffers from the disorder can be different. It is for this reason that Autism Spectrum Disorder is actually a group of disorders that result in similar symptoms. These disorders include Autistic disorder, Asperger syndrome, and pervasive developmental disorders that are otherwise unspecified. Autistic disorder is what the general population normally thinks of when they think of autism, and it normally consists of the most severe symptoms. Asperger syndrome, unlike autistic disorder, usually causes symptoms that mostly affect social behaviors, and the people who suffer from it can have normal or even above-average intelligence and language skills. The common signs and symptoms of ASD are related to communication, social behaviors, and routines. Some of the signs that fall into the communication category include not responding to one's name by the age of 12 months, showing delayed speech or slowly developed language skills, and not following directions. Additional signs of ASD include not smiling when smiled at, being very independent for one's age, preferring to play alone, repeating words or actions, and spending a lot of time putting things in a certain order. Estimates about the prevalence

of autism in the United States suggests that approximately 1.5% of children are affected by the disorder. (Autism) It must be noted that these are estimates, not known statistics, and that while 1.5% of children may have the disorder, not every one of these children suffer from an intellectual disability because of it.

History of intellectual disability diagnostic procedures

As of 2002, the American Association of Intellectual and Developmental Disabilities considers an individual to have an intellectual disability if he or she meets each of the following criteria: his or her IQ is below 70-75, he or she suffers from significant limitations in two or more adaptive areas, and the condition manifests itself before the age of 18. For the purpose of diagnosis, adaptive areas are considered to be any of the skills that are needed to live, work, and thrive in a social environment. Examples of these are communication, self-care, and the ability to follow social norms. If an individual meets all three criteria, he is considered to be intellectually disabled (What is Intellectual Disability). They also define intelligence as the general mental capacity that involves reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning efficiently, and learning from experience (AAIDD, 2010).

While ID diagnosis is currently based off this definition in the United States and in many other countries around the world, the official definition of intellectual disability has changed a lot over the years. The American Association of Intellectual and Developmental Disabilities, known previously as The American Association for the Study of the Feeble-Minded when it was founded in 1876 and the American Association on Mental Retardation (AAMR) in the 1990s, has grown and transformed its definition according to the changing times. For example, in the early decade of the twentieth century, the definition of a "feeble-minded" person was centered on intelligence level and the opinion of professional psychologists. For this reason, one of the main diagnostic tools used during this period was an intelligence test, and one's score on this test determined both if he was feeble-minded and to what severity. In 1992, AAMR shifted its definition once again, changing the term of the disorder from feeble-minded to mental retardation. The definition of mental retardation referred to "substantial limitations in present functioning," and was characterized by "significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health

and safety, functional academics, leisure, and work, that manifests before age 18" (Trent, 2017). This new classification was groundbreaking, as it turned the previous definition of ID—an absence of measurable general intelligence—into a functioning definition based on several specified contexts of everyday life that could not just be measured by the old intelligence test tool. The new classification of 1992 brought the definition of mental retardation away from an individual's deficit of intelligence. This definition was modified and strengthened in 2002 to become the definition that ID diagnosis is based on today and, in line with the changing times, the name mental retardation was changed to intellectual disability shortly after in 2005. Not everyone, however, was on board with this progressive definition. In 2006, a volume of essays titled *What is Mental Retardation? Ideas for an Evolving Disability in the 21st Century* demonstrated the resistance of psychologists to accept the new definition, as well as the new term, by continuing to link general intelligence as the central tool for defining ID. Above all, this volume of essays shows how, while the official definition and related diagnostic procedures may have been changed, the act of putting these changes into everyday practice was drawn out by psychologists and practitioners who preferred the old method. As 1999 was in the middle of a period of transition concerning both the definition and diagnosis of intellectual disability, it is possible that some professionals were still using older diagnostic methods, leading to possible inconsistency. As there is not much information available concerning the specific diagnostic procedures, and their standardization, that took place in Spain in 1999, one should keep in mind that the 90's and the early 2000's saw a major period of change in society's perception of ID.

Diagnosing intellectual disabilities—and disabilities in general—differs depending on the age of the person. For example, in children under the age of six it is very had to know if a disability is going to be temporary or if it will continue affecting the child over a large duration of time. There are many factors that must be considered when diagnosing young children with disabilities. First, young children are just developing their language, motor, and social skills. With this said, it is hard to differentiate between a temporary developmental delay and a long-term disability. Additionally, some signs of disorders that are known to cause intellectual disabilities—such as Autism Spectrum Disorder—require the observation and analysis of things such as social behaviors, which a young child has not had adequate time to develop. In other words, it is hard to determine if a child has an intellectual disability that is undetectable at the current moment. Relying on observations

made before a child has reached a more mature developmental phase can lead to less accurate predictions of intellectual disability. On the opposite spectrum, diagnosing disabilities (excluding intellectual) is also more difficult after one reaches the age of 65, as a disability to do something such as taking care of oneself could be caused by the natural aging process and not an actual deficit.

Since the information collected and analyzed in this study are from Spain, the following section is dedicated to the history of the ID diagnostic procedures in Spain. Spain is divided into 17 autonomous regions which each have their own government and administration, including autonomy in health and social services. The social services transfer was completed by 1997, and the completion of the health service transfer followed in 2001. Because of this, Spain has a decentralized health system. For example, Catalonia, one of the autonomous communities, develops and executes a Health Plan for Catalonia which explains the budget, objectives, lines of action, and projects that the autonomous community wishes to achieve over the following four years. With this said, it must be remembered that not only the environmental factors, but the social factors as well, can be different among the autonomous communities. While one community may put an emphasis on addressing mental health, another may emphasize the importance of treating the increasing number of chronic conditions. Table 1 lists some of the instruments that are commonly used in Spain to diagnose intellectual disability.

Age Range	Instruments
Infancy and Adolescence	BSID (Bayley Scales of Infant Development) MSCA (McCarthy Scales of Children's Abilities) WPPSI (Wechsler Preschool and Primary Scale of Intelligence) WISC (Wechsler Intelligence Scale for Children) KABC (Kaufman Assessment Battery for Children)
After the age of 16	WAIS III (Wechsler Adult Intelligence Scale)

Table 1. Instruments used in Spain to evaluate general intelligence and psychomotor development. (Navas, 2008)

Levels of intellectual disability. Most ID diagnostic systems classify the severity of the disability in relation to the level of support one needs to achieve his or her optimal personal functioning. People who are diagnosed with ID are then further classified as either mild, moderate, severe, or profound. People on the verge of intellectual disability are often classified as having a limited intelligence. Different classification systems sometimes use different criteria to distinguish between the severity levels of ID. For example, the Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV), published in 1994, used IQ categories to determine severity levels. The most recent version (DSM V), published in 2013, classifies severity based on the ability to accomplish daily skills. If the regulations set in place by the American Association of Intellectual and Developmental Disabilities are used, then severity is classified by the intensity of support needed. Table 2 shows the most common criteria for the severity categorization of intellectual disability.

Severity Categorization of Intellectual Disability			
	IQ	**Daily Skills**	**Intensity of Support Needed**
Mild	50-69	Can live independently with minimum levels of support	Intermittent support needed during transitions or periods of uncertainty
Moderate	36-49	Independent living may be achieved with moderate levels of support; group homes	Limited support needed in daily situations
Severe	20-35	Requires daily assistance with self-care activities and safety supervision	Extensive support needed for daily activities
Profound	<20	24-hour care	Pervasive support needed for every aspect of daily routine

Table 2. Guidelines used for the categorization of intellectual disability severity level based on three different, commonly referenced systems of ID diagnosis.

Other deficits present in people with intellectual disability

A deficit is defined as any loss or abnormality of an organ or its functions. Often, people with intellectual disability also suffer from a different, non-related deficit which can further impact their quality of life. For the purpose of this study, each individual deficit can be classified as belonging to one of the following eight categories.

Nervous system deficits. There are many different deficits which can result from the loss of nervous system functions. These deficits are separated into six different

categories: superior extremity paralysis, inferior extremity paralysis, paraplegia, tetraplegia, movement coordination disorders, and other.

Visceral deficits. A person is considered to have a visceral deficit if they suffer from a loss of function in the respiratory system, the cardiovascular system, the digestive tract, the genitourinary tracts, the endocrine system, or the immune system.

Mental deficits. A person who already has an intellectual disability is considered to have a mental deficit if they also have a mental illness that is independent of the original disability. Some examples of a mental deficit include mental delays and dementia.

Visual deficits. A visual deficit is defined as any deficit that stems from the visual organs. This could include total blindness or bad vision; however, bad vision that can be corrected with the use of glasses or contact lenses is not considered to be a deficit.

Auditory deficits. Examples of auditory deficits are deafness, bad hearing, and equilibrium disorders.

Language, speech, and vocal deficits. A person is considered to have a language, speech, and vocal deficit if they are mute or show signs of difficult or incomprehensible speech.

Osteoarticular deficits. Osteoarticular deficits deal with abnormalities in the head, spine, superior extremities, and inferior extremities.

Other. Other deficits that fall outside of the previously stated categories include deficits of the skin and deficits that are hard to classify as falling under a previously determined category. Additionally, a person who suffers from more than one deficit could also be classified as part of the *other* category.

Background of environmental and social factors in Spain

Quality of life. One example of how taking real data concerning intellectual disability into account could be beneficial to future social program development is in the case of multimorbidity. Multimorbidity is defined as having two or more chronic conditions, and multiple studies have linked the prevalence of multimorbidity with both severe/profound intellectual disability (especially down syndrome) and age. Because of this, if the actual prevalence of ID is considered, it is easier for a government to efficiently create targeted, proactive prevention and treatment programs and make them available to

the populations that need them most. While multimorbidity normally occurs at a much higher rate in people who are older, the percentage of people with ID with multimorbidities spikes at a much younger age than in the general population. The ID population has demonstrated an early occurrence of geriatric frailty, showing mean frailty index scores at the ages of 50-59 that are comparable to those aged 70-79 in the general population. Some of the probable causes of these signs of early aging in people with intellectual disabilities are developmental problems, metabolic effects of antipsychotic use, or unhealthy lifestyles. In a study done by Heidi Hermans and Heleen Evenhuis (2014) in the Netherlands, it was found that multimorbidity was present in 79.8% of a population of people with ID who were over the age of 50. Additionally, 46.8% of those were found to have four or more chronic conditions. Three trends were evident from their results: the prevalence of multimorbidity increases with age, people who suffer from either severe or profound ID have a higher rate of multimorbidity, and those with Down Syndrome often had four or more chronic conditions. For comparison, only 56.4% of community-dwelling older people without intellectual disability suffered from multimorbidity. A study done by Martínez-Leal et al. (2011) in Spain corroborates the link between ID and multimorbidity. Results of the study show that more than 22.5% of the ID sample had epilepsy while only 0.85% of the general Spanish population suffered from the same condition. Additionally, the percentage of obesity in the ID population (33.3%) was double that of the general population (15.56%), and the rate of psychotic disorders was 9.2% compared to 0.29% (Martínez-Leal, 2011). This data is a good foundation for health professionals in Spain and abroad to use when treating patients with ID, as it gives three specific chronic conditions that occur at a much higher prevalence and need to be monitored on a closer level.

Many conditions—such as severe challenging behavior, cardiovascular diseases, diabetes II, depression, and anxiety—could be delayed or even prevented with the help of proper programs dedicated to detecting and treating common risks found in the ID community at an earlier age than the general population. An example of a program that could highly benefit people with intellectual disability would be a support center that helped them deal with their emotional problems and insecurities—especially those specific to the hardships of overcoming obstacles with an intellectual disability—to help prevent

the onset of depression or anxiety. As both disorders are chronic conditions that can also cause other disabilities, it would be beneficial to develop programs for their prevention.

Considering the data showing that people with ID have both higher mean frailty index scores and higher incidences of multimorbidity at a younger age than the general population, it is no surprise that the life expectancy of the ID community is lower than that of the general population. In England, the life expectancy for men and women with ID is 63.5 years and 66.7 years, respectively. In contrast, the life expectancy for the general population is 83.6 years for men and 86.9 years for women (Glover, 2017). In a study performed by Glover et al. (2017), the death rate for people with ID was found to be over three times that of the general population in England. Diseases of the circulatory system were responsible for the largest number of deaths of people with ID. These diseases include ischemic heart disease, cerebrovascular disease, phlebitis and thrombophlebitis, cardiomyopathy, and pulmonary embolism. While 53 deaths were expected based on numbers taken from the general population, 152 were observed (Glover, 2017). The second largest cause of death in the ID population was due to problems with the respiratory system, such as influenza and pneumonia (114 observed, 23.3 expected). As stated in the article, the Office for National Statistics reported that 44.7% of people with ID who died in 2013 in England died of avoidable causes, as opposed to 21% of the general population. Of these preventable causes of death—especially in younger people with ID—suicide, accidents, and alcohol related disorders were the most prominent. While the results of this study are intriguing and help to show the possible advantages of tailoring social programs towards the prevention and treatment of specific diseases—and at specific ages—in the ID community, one should be cautious when comparing these results internationally. It is always difficult to compare the results of health-related studies internationally due to different health care systems, recognition thresholds, and environmental conditions that may affect the initiation or progression of a disease. Nonetheless, the results of this study can be used as evidence that more programs should be dedicated to the prevention of avoidable deaths in the ID community, and even provides an insight into the leading causes of death that should receive extra attention.

Legislation. The Spanish law for the Social Integration for the Handicapped (LISMI) legally defines a handicap as the existence of a “decrease in the physical,

psychological or social abilities as a consequence of a deficit which may be permanent, and which may have or may not have a congenital basis" (European Intellectual Disability Research Network, 2003). A Royal Decree, issued in December of 1999, defined the procedure for legal recognition and grading of handicaps (procedimiento para el reconocimiento y calificación del grado de minusvalía). The decree states that "the legal status of handicapped is provided by the official agencies which are accredited for such tasks." The decree allowed for handicaps to be graded by assignation of a percentage to a person through the consideration of both medical and social factors. The grading was mainly based off the WHO 1980 classification of impairments, disabilities and handicaps (CIDDM-1980). The percentage index of handicap is decided by an official assessment team, and the coding can be used by the handicapped person for entitlement and legal issues. (European Intellectual Disability Research Network, 2003) As this new procedure was put into effect at the end of 1999, a small percentage of the change in prevalence between 1999 and 2008 could be due to possible changes in both diagnosis and recognition of ID within the Spanish population.

Work and Education. People with disabilities often fall into a societal sector which is confronted with a large variety of obstacles that impede equality of opportunities, independence, and full societal integration. Because of this, it is important that communities take the necessary actions needed to facilitate the integration of people with disabilities—including intellectual disabilities—into society. One of the underlying objectives of the Disabilities, Deficits, and Health State survey of 1999 was to contribute accurate information towards determining the existing socio-sanitary differences between people with and without disabilities (Comparación). This information was collected with the intent of being used to help eliminate both physical and psychological barriers, facilitate access to education, and help the ID community enter the work force. Some of the information collected from the survey for the purpose of improving programs and legislation within Spain include data relating to household dynamics, education, and employment. While the main focus of this work is on the epidemiology of intellectual disability in Spain, the following information includes all types of disabilities in order to provide a better analysis of the obstacles the disabled population face as a whole.

The first category of information collected helped bring to light the dynamics of households with and without disabled residents. One interesting statistic included under this category is the percentage of people either married or living in pairs in the disabled population compared to the percentage found in the general population. These percentages give important information about the existence of an equal opportunity to marry, especially within the younger generations. Additionally, the percentage of older people with disabilities who live in pairs represents the number of people who live with someone that can help care for them if they have trouble fully taking care of themselves. The results of the survey show that at all age groups, people without disabilities lived in pairs at a higher rate than those with disabilities (Comparación). For example, in the 60 and over age group, the probability of a disabled woman being married was 31% lower than that of women without a disability. While this could be a result of premature geriatric frailty leading to a higher number of widows at younger ages, it is also possible that other factors play a role in this difference. The percentage of married men over the age of 60, however, is similar in both the disabled and nondisabled populations. Even more useful than statistics on the percentage of disabled people either married or living in pairs is the number of disabled people who live alone. These statistics can be used as a useful source of information about the possible level of help the disabled population may need from the general community, as it refers to a population that may not be completely autonomous. The survey found that the percentage of people with disabilities living alone was more than double that of those without disabilities in the 40-59 age range, and 50% higher between the ages of 60 and 79. (Comparación) These percentages should be used by the Spanish government to properly allocate their resources into the correct public care programs.

Another interesting way to measure societal integration is through education. A person's level of education is a good indication of how easy it will be for them to find work, and often acts as a level of personal qualification. The results from the survey show that, in 1999, 44% of the general population between the ages of 18 to 44 had finished high school or higher, while only 18% of the population with disabilities in this age range had completed the same. When considering the different factors that may result in educational differences, one needs to take into account not only the type of disability

(disabilities that affect a person's capacity to learn, such as mental disorders, auditory disabilities, visual disabilities, or communicative disabilities impose an added difficulty to the completion of the normal education process) but also the scholastic integration and social acceptance children with disabilities need, but often lack, from their peers. Doing a broader analysis, it was found that while 99.85% of men and 99.79% of women were literate in the general population, 12.55% of the disabled population between the ages of 10 and 44 were illiterate. In this age range, many people with disabilities are illiterate because of physical or mental problems. As literacy is a very important skill to have if you want to function independently in society, the difference in the prevalence of illiteracy between the two populations is tangible evidence of the disadvantages that people with a disability may face in terms of social integration.

This leads to one of the most important determining factors of social integration: employment. One of the basic priorities of most people—especially those with disabilities—is to be employed. For those with disabilities, access to the work field and labor integration are fundamental aspects of social integration, and it is important that programs and laws are set in place that help make the labor market equally obtainable for them. In Spain in 1999, The most striking distinction between the disabled population and the general population was within the 25 to 44 age range. While men in the general population were found to be employed at a rate of 85%, only 39% of disabled men in the same age group were employed. Overall, people between the ages of 16 and 64 in the general population had a 55% employment rate, compared to the 26% employment rate of the disabled population. The inequality that people with disabilities face in the work field is not exclusive to Spain. A 2004 United States survey reported that while 78% of the general working-age population were employed, only 35% of those with disabilities in the same age group were working (Disabled World Statistics). These results demonstrate that while certain legislation may already exist in Spain and in other parts of the world, more programs are needed that dedicate their time and resources to helping people with disabilities find, obtain, and retain work.

An article written by Carter, Blustein, Bumble, Harvey, Henderson, and McMillan (2016) suggests a new approach to integrating the ID population into the labor market. It was reported that only 26% of recent high school graduates in the United States with

severe intellectual and developmental disabilities were working for pay within the first two years after graduation (Carter, 2016). As mentioned in the article, this statistic was calculated after nearly 25 years of federally mandated transition services. It is clear that a different kind of action needs to be taken towards the transition of intellectually disabled young adults into employment. One option they are pursuing is called community conversation, based on the World Café model, which centers around the idea of engaging the entire community to come up with ideas and methods that further help the intellectually and developmentally disabled (as well as the generally disabled population) find and obtain paid work opportunities. Providing community members with the chance to take the future of their work field into their own hands has many possible benefits, including the ability to focus on new ideas that better fit the community rather than continuing to build transition programs on previously existing models that may not accentuate the community's already existing resources. Additionally, community conversations provide an outlet for the community to propose both formal and informal solutions that reflect the priorities of the community in question. When analyzing the results of six community conversations held in different towns in Tennessee, the most common strategy suggested was developing new employment opportunities for people with disabilities. An example of one of these strategies was providing a free online course designed to educate employers on disabilities and accommodations in the work place. Another suggestion was to formally acknowledge businesses who show advancements towards employing youth with disabilities. A second common strategy was to increase community-wide efforts to develop local employment opportunities for the disabled population. For example, one suggestion was to use the local media to address common misconceptions about hiring people with disabilities, as well as to share success stories of disabled people who excelled at their jobs. The idea of holding community conversations to help solve the employment inequality problem that people with disabilities face should be looked at in further detail as, ultimately, most intervention programs are delivered through local means anyways. It is often quicker and more efficient to work at the level of individual communities, as they are more aware of the resources they have and the outcomes they wish to obtain. The results of this article should be taken into account when trying to develop or enhance community-wide programs with the intent of closing the

employment gap between the disabled and the general populations. This, in combination with real, accurate data concerning different aspects of the disabled community, proves a promising method for inducing positive change towards the social integration of people with disabilities in Spain and around the world.

Materials and Methods

General

This study was descriptive, observational, cross-sectional, and analyzed retrospectively. The data used were obtained from the microdata archives of the 1999 poll Discapacidades, Deficiencias y Estados de Salud (Disabilities, Deficits, and Health State) given out by the Instituto Nacional de Estadística (INE). The data can be found on their web site. The microdata archives were transformed utilizing syntax archives created by Josep Pascual, and the descriptive analysis was executed with SPSS. Afterwards, statistical analysis was done to compare the data obtained from the 1999 survey to the data obtained in the 2008 survey.

Disabilities, Deficits, and Health State Survey (1999)

Participants. This investigation covered the population of people who reside in family housing in all of Spain. There was a sample size of 80,000 houses distributed throughout 3,000 census sections. Residences were chosen with respect to district location. A general questionnaire was given to each of the homes included in the sample and, if a disability was detected, a second survey was given to each person who suffered from a disability. The Disabilities, Deficits, and Health State survey was given to every person who suffered from a disability and was over the age of six, while the Limitations and Deficits questionnaire was given to anyone under the age of six who showed signs of disabilities.

Design. In this survey, disability was defined as the limitation of a human capacity that originates in a deficit, makes it impossible to perform or that seriously hinders the normal activity of a person, and has affected or is expected to affect this activity for more than one year (INE, 1999). A person was only considered to be disabled if they had difficulty doing any of the 36 daily life activities that appear in Disability Card B (la Tarjeta B de Discapacidades). For the purpose of this study, an activity was determined to be seriously hindered if the person interviewed considered it to be. In the analysis of

comorbidities, one was only considered to have a second, unrelated deficiency if the second disorder limited his or her daily activities more than the intellectual disability did. The survey used a stratified two-stage sampling, where the units of the first stage were census sections and the units of the second stage were family housing. Stratification was accomplished by first dividing Spain into 52 provinces (including Ceuta and Melilla) and then splitting each province up into nine different types of strata, depending on each section's demographic importance to the municipality it belongs to and its socioeconomic worth. The strata details can be found in Table 3. Within each stratum, the houses were selected with equal probability by the means of systematic random sampling. (INE, 1999)

Stratum 1	*Capital of each province*
Stratum 2	*Self-represented municipalities (important to the capital)*
Stratum 3	*Other self-represented municipalities with more than 100,000 residents*
Stratum 4	*Population between 50,000-100,000*
Stratum 5	*Population between 20,000-50,000*
Stratum 6	*Population between 10,000-20,000*
Stratum 7	*Population between 5,000-10,000*
Stratum 8	*Population between 2,000-5,000*
Stratum 9	*Population less than 2,000*

Table 3. Strata Classifications for the Disabilities, Deficits, and Health States Survey

Procedure. The data was collected during the second trimester of 1999 over a duration of approximately three months. The principle method of data collection was personal interview. The interviewers visited the houses to perform the interviews and give the surveys to each participant. In cases where information was missing or errors were found in the data provided, follow up phone calls were made in addition to the personal interview. The Disabilities, Deficits, and Health States survey was given to each resident who was found to have a disability after participating in the first step of the investigation, the home questionnaire. If the resident was under the age of six, they were given the Limitations and Deficits questionnaire instead. (INE, 1999)

Results

As shown in Table 4, the 1999 survey resulted in an estimated total of 154,796 people who were diagnosed with an intellectual disability. The estimated prevalence of ID in Spain (excluding those in institutions) was 0.39%. Within the ID population, 96.52% were between the ages of 0 and 64, and 3.48% were 65 or older. Of the total number of intellectually disabled people, 32,108 of them had Down syndrome. This makes the total prevalence of Down syndrome within the intellectual disability population 20.74%, 95% CI [20.54, 20.94]. After analyzing the data provided regarding the age of the mother when the subject was born, it was found that 75.4% of the intellectually disabled population were born to mothers who were under the age of 35, and 24.6% were born to mothers who were 35 or older. When considering only those with Down syndrome, however, it was determined that 52.4% of the people with Down syndrome were born to mothers under the age of 35, and 47.6% were born to mothers who were 35 or older. The sex ratio for intellectual disability was 1.34, and the sex ratio for Down Syndrome was 1.03. Graph 2 presents the information obtained regarding the types of deficits found in the six and older ID population. While 72.75% of the ID population were not found to suffer from any other deficits, 27.25% did. Of this 27.25%, 8.50% were classified as visual deficits, 6.71% as osteoarticular deficits, 5.25% as auditory deficits, 3.45% as nervous system deficits, 1.56% as language or speech deficits, 0.89% as mental deficits, 0.56% as visceral deficits, and 0.33% as other.

The 2008 survey outcomes, presented in Table 5, show that the total estimated number of people with intellectual disabilities in both residential housing and institutions was 197,596. The total estimated number of people with ID taken only from residential housing was 162,2251. The prevalence of ID in Spain was 0.44%, while the prevalence of ID in only the residential houses was 0.36%. Within the ID population who lived in residential housing, 92.89% were between the ages of 0 and 64, and 7.11% were 65 or older. Of the total number of intellectually disabled people, 36,944 of them had Down syndrome. Thus, the total prevalence of Down syndrome within the intellectual disability population, including the information taken from institutions, was 18.70%, 95% CI [16.42-20.97]. The prevalence of Down syndrome found using data collected only from

the houses was 21.29%. The sex ratio for intellectual disability was 1.45, while the sex ratio for Down syndrome was 1.35. While 76.43% of the ID population were not found to suffer from any other deficits, 23.57% did. Of this 23.57%, 7.55% were classified as visual deficits, 4.80% as osteoarticular deficits, 5.75% as auditory deficits, 6.55% as nervous system deficits, 3.34% as language or speech deficits, 2.07% as mental deficits, 3.39% as visceral deficits, and 1.09% as other.

Statistical analysis was also done to compare the results obtained from the 1999 and 2008 surveys, the results of which can be found in Table 6. The chi squared test was used to determine if a significant difference existed between the ID prevalence within the general population of Spain between the two years. Including the ID population from the institutions surveyed in 2008, the relationship between the two variables was significant, X^2 (1, N=218,185) = 10.25, p<.01. The prevalence of ID in 1999 (0.39%) was lower than in 2008 (0.44%). Performing the test excluding the data collected from the institutions in 2008 again gave a significant difference between the two years, X^2 (1, N=218,185) = 7.29, p<.01. In this case, however, the prevalence of ID in 1999 (0.39%) was significantly higher than in 2008 (0.36%). Chi squared was also used to analyze the change in the prevalence of Down syndrome in the family housing only between the two years. The relationship between the two variables was not significant, X^2 (1, N=981) =0.021, p=0.88. The prevalence of DS within the ID community in 1999 (20.74%) did not differ significantly from the prevalence seen in 2008 (21.29%). When analyzing the data by age group, it is found that 3.48% of the ID population in 1999 were 65 or older, while 7.11% were 65 or older in 2008. With regards to Down syndrome, 17.85% of the total number of people with the disorder were over the age of 40 in 1999, while the same age group represented 24.62% of the DS population in 2008. Both sections demonstrate an upward trend in the percentage of people with ID at an older age.

Discussion

As presented in the results, there is, overall, a significant difference between the prevalence of intellectual disability in Spain between 1999 and 2008. This increase could be a result of the combined effect of multiple different factors, including the emergence of new diseases, the increasing life span of the population, and changes in the diagnostic

procedure over time. While this work focuses mainly on intellectual disability, it is also interesting to compare the trends found in the ID population with the disabled population in general. Multiple studies have found evidence of an upward trend in the number of people with disabilities in general not only in Spain, but in many different countries around the world as well. One example of this is demonstrated in the Brazilian census, which shows only a 1-2% disability rate in 1991, but a 14.5% disability rate in 2001. In just 10 years, the disability rate increased by about 12%. Similar jumps in the prevalence of disability have also been recorded in Turkey (12.3%) and Nicaragua (10.1%) (World Disability Statistics). According to the International Labor Organization (ILO), claims for disability benefits are surging by up to 600% in industrialized countries (World Disability Statistics). This substantial increase in the need for benefit programs has encouraged both governments and private companies to search for ways to help keep the disabled population socially integrated and employed. The best way to create programs that are both efficient and effective is to base their development on data that accurately represents each society's individual needs. The survey on Disabilities, Deficits, and Health State, given in 1999, and the survey on Disabilities, Personal Autonomy, and Situations of Dependence, given in 2008, help to accomplish just that for the Spanish population.

One of the most likely factors of the increase in disability—including intellectual—is our steadily increasing life span. It is estimated that in approximately five years, the number of people over the age of 65 will outnumber the number of children under the age of six. This phenomenon is due to the quick acceleration of population aging and the increasing quality of global health care. (Suzman, 2011) As a result of the increase in people aged 65 or older with chronic conditions, there has also been an increase in disability. An increase in dementia has been noticed specifically, and it is estimated that 20-30% of people over the age of 84 are affected by it (Suzman, 2011). Additionally, poor early life conditions have been linked to a higher disability prevalence at a rate of 43%. As many members of the older population were raised in poorer conditions such as wars, the great depression, and lower living conditions, it would follow that a higher percentage of them would end up developing disabilities.

In the case of intellectual disability specifically, the increasing life span could have an impact on the number of children born with brain defects. As the life span of a population increases, the average age a mother gives birth to her first child increases as well. As exemplified in many studies—specifically those which study Down syndrome—the older a mother is at the time of birth, the higher the chance of an abnormality occurring during the early developmental process. One environmental theory about why increased maternal age increases the risk of infertility, chromosomal aberrations, increased copy number variations, and congenital malformations is that environmental exposures lead to acquired changes which are encoded within the double helix of the DNA. These epigenetic changes can dictate gene expression patterns in subsequent generations, which could lead to disorders such as ASD or Down syndrome. (Shelton, 2010) Another theory, specifically for ASD development, is that older parents might be more likely to seek diagnoses to explain any abnormal behavior in their child. An example of the correlation between maternal age and increased ID is seen in the study done by Shelton et al. in 2010. Their results—analyzed from a 10-year California birth cohort (1990-1999)—linked advanced maternal age to an increased risk for autism monotonically. Compared with mothers between the ages of 25 and 29, mothers age 40 or older were 51% more likely to have a child with autism (aOR 1.51). From their results, they calculated that the recent upward trend in childbearing age was responsible for approximately 4.6% of the increase in autism diagnoses in California. (Shelton, 2010)

While there is a lot of literature documenting the rise of disabilities in countries around the world, it is impossible to determine if the prevalence of intellectual disability in Spain has actually increased between the years of 1999 and 2008 because of the addition of information from institutions in 2008 which is missing from the 1999 data. Although the difference in prevalence between the two years is statistically significant, it is very likely that this increase exists partly because there were more people surveyed in 2008, and this increase in sample size included a very biased population towards ID: institutions. Additionally, there is not much data available on the number of people with ID who were institutionalized in 1999. Without this information, it is difficult to determine if the prevalence of ID in institutions around Spain increased as well. For this reason, and to maintain consistency throughout the comparative analysis, any conclusions drawn in this

study surrounding the change in ID prevalence in Spain from 1999 to 2008 will come from the data collected in both surveys from residential homes only. This changes the total amount of people with intellectual disability in 2008 to 162,251 instead of 197,596, giving an ID prevalence of 0.36%. As shown in the results, the change in prevalence between the two years without the inclusion of data from institutions is also significant; however, the prevalence is now shown to have significantly decreased. There are a few factors which could have led to this decrease, including a decrease in the incidence of Down syndrome and the influx of foreigners who came to study, work, and live in Spain over these 10 years.

The first factor which must be taken into consideration is the decreasing incidence of Down syndrome (DS). As seen in Table 5, the number of children age 0-9 with Down syndrome in 1999 (5,086) is greater than the number of children in the same age group with Down syndrome in 2008 (3,623). One of the biggest reasons for this could be due to an increase in the number of mothers who abort their fetus if it tests positive for trisomy 21. In 1994, an invasive diagnostic test was introduced that could prenatally diagnose Down syndrome. While introduced in the mid-1990s, due to its invasive nature, the test did not gain momentum until the beginning of the 21st century. To determine the impact this diagnostic test had—and continues to have—on the number of live births of children with DS, the rate of terminated pregnancies within the number of prenatal diagnoses given must be analyzed. One great source for tracking birth defects is the National Down Syndrome Cytogenetic Register (NDSCR). Part of the EUROCAT—a broader European network of population-based registries that compiles epidemiological data on congenital anomalies throughout Europe—this register is an accurate source of data concerning prenatal diagnosis and termination rates of DS in England and Wales. When using information gathered from all member registries, it was found that there were 4,288 live births of children with DS, 5,215 terminations, and 231 fetal deaths between the years of 2008 and 2012 (Bradford, 2015). This shows that 53% of pregnancies with a DS diagnostic were terminated. In a study conducted by Graaf, Buckley, and Skotko concerning the prevalence of DS termination in the United States, they estimated that the average number of live births of children with DS between the years of 2006 and 2010 was 5,300 births per year, and the average number of pregnancy terminations following

prenatal diagnosis per year was 3,100. This estimates the rate of pregnancy termination to be approximately 37%. The authors also estimated that pregnancy termination after prenatal diagnosis of DS results in a 30% reduction in overall DS births in the United States. An interesting observation the authors make is that the estimated prevalence of DS in the United States, excluding termination and natural loss, is 1 in 365, which closely correlates with the documented live birth incidence of DS in the Arab world, where abortion due to prenatal diagnosis of DS is not allowed. (De Graaf, 2015) Overall, literature has found that the increase in prenatal diagnosis of DS has led to a higher number of pre-diagnosed abortions and a reduction in the overall live births of children with Down syndrome. These statistics show the number of DS pregnancy terminations that occurred using the invasive diagnostic test, and can be used as a benchmark to estimate a possible future increase in prenatally diagnosed DS termination after full integration of new, noninvasive prenatal screening (NIPS) technologies introduced in the end of 2011.

The last, and probably most important, factor that may have contributed to a decrease in ID is the influx of foreigners in Spain. Data shows that the number of foreigners living in Spain was only 748,955 (1.86%) in 1999, in comparison to 5,268,762 (11.41%) in 2008. This is a significant increase in the prevalence of foreigners, which could definitely impact the ability of the data collected in 2008 to be completely comparable to the Spanish population found in 1999. The majority of the foreigners who lived in Spain in 2008 were between the ages of 20 and 50, which insinuates that they had moved to Spain in order to either study or work. It is very unlikely that one would move to a different country to work or study if they suffered from some sort of disability, especially an intellectual one. If this were true, it would follow that the non-intellectually disabled “Spanish” population had been disproportionately increased, which could have played a major role in the perceived decrease in ID prevalence in residential homes in 2008 in comparison to 1999.

Conclusion

When comparing the results on intellectual disability obtained from the national surveys given to family residences in 1999 and 2008, a significant decrease in the prevalence of ID is found. The prevalence decreases from 0.39% in 1999 to 0.36% in

2008. There are two main contributing factors to this decrease in prevalence: the gradual decrease of children born with Down syndrome and the influx of immigration Spain faced within this 10-year time frame. As discussed above, the introduction of a diagnostic test designed to prenatally diagnose Down syndrome has been strongly linked to a large increase in pregnancy termination. Because of its invasive nature, the exam did not gain full momentum until the beginning of the 21st century, during the exact period between the 1999 and 2008 surveys. As the diagnostic test increased in popularity—and as the right to abort became more prevalent—the rate of prenatally diagnosed terminations also increased in many countries around the world. Additionally, the data collected from the 1999 survey regarding a mother's age at the time of conception is consistent with other sources that show an increase in the probability of conceiving a child with Down syndrome over the age of 35. As seen in the results, almost half of the people surveyed who had Down syndrome were born to mothers over the age of 35. Modern medicine has begun to take statistics like these into account, due to their high rate of replicability. In many countries, it is highly recommended that women over the age of 35 do the prenatal diagnostic procedure in order to determine if their child has the disorder or not. While the average age of conception has been steadily increasing over the past two decades, so have the abilities of modern medicine; as a result, women are now able to choose if they want to bring a baby with Down syndrome into this world no matter what their supposed risk is. This technology proves a viable contributing factor to the significant decrease observed in the results.

In terms of Down syndrome, the change in prevalence within the ID community in the family housing samples was not significantly different between the two years. However, when the age groups are broken down, clear trends exist. First, the percentage of people with Down syndrome between the ages of 0 and 9 decreased from 15.84% in 1999 to 10.60% in 2008. As discussed previously, one of the main contributing factors to these numbers is the increase in pregnancy terminations due to prenatal diagnosis of DS. Researchers in the United States estimate that the introduction of diagnostic tests which can accurately determine the presence of Down syndrome has led to a 30% decrease in the new DS population. The decline in the number of children born with Down syndrome as the years progress should be monitored, as new, noninvasive procedures are being introduced into health systems around the world.

On the other hand, the percentage of the DS population living in residential housing aged 40 or older increased from 1999 (17.85%) to 2008 (24.62%). The most

likely contributing factor to this increase is the overall rise in life expectancy seen both in Spain and across the world. As population aging accelerates, the average life expectancy of people with Down syndrome (as well as people with all types of intellectual disabilities) also increases. The trends found when comparing the data from the two different surveys are consistent with the expected percentages based on the general rise in life expectancy. Having a higher percentage of people with Down syndrome represented in the age groups over 40 shows that, on average, people with Down syndrome in 2008 are living longer than they did in 1999 and in the years before.

Overall, it appears that the two different factors—a decrease in the number of new Down syndrome cases and an increase in the average life expectancy of a person with DS—counteract one another. It would be interesting to see if, in the present day, both forces still counter one another or if one factor has begun to take precedence. When considering the potential contributing factors to the prevalence of intellectual disability, any change in the prevalence of DS is very important. As shown through these surveys, an average of 20% of the people with ID suffered from Down syndrome between the years of 1999 and 2008. This is a large percentage of the ID population; therefore, changes to the Down syndrome population play a major role in the prevalence of intellectual disability in general.

A second factor that could account for the decrease in the prevalence of ID shown in the results is the increase of non-disabled immigrants between the ages of 20 and 50 who had entered Spain to either study or work during this period. As stated before, it is very unlikely for someone to move to a different country in search of employment or to further their education if they have a disability, especially an intellectual disability. For this reason, it is reasonable to deduce that the non-intellectually disabled "Spanish" population had been disproportionately increased over the course of these 10 years, playing a major role in the perceived decrease in the prevalence of ID. Although it is difficult to know the extent to which this factor may have influenced the results, it is probable that without the aforementioned influx of immigrants, the prevalence of intellectual disability within the general population of Spain may have even shown a slight increase over the years, as seen in other Spanish databases.

As mentioned in the introduction, according to the National Database of People with Disability, the recorded prevalence of intellectual disability within the general Spanish population in 2013 was 0.50%. In 2015, the database showed the recorded prevalence of ID to be 0.57%. Considering the database alone, it seems as if the

prevalence of ID in Spain has been slowly increasing. As the National Database of People with Disability only reflects the number of people who possess an official certificate of disability, the number of people registered with ID can only be used as an estimate of the actual ID prevalence that exists. With that said, it is very likely that these numbers include the people with intellectual disability who reside in institutions, which makes the database a viable source of comparison for the numbers retrieved from the national survey of 2008. This type of source would be comparable to the estimated ID prevalence found in all of Spain from the 2008 survey, showing a general increase from 0.44% in 2008, to 0.50% in 2013, and 0.57% in 2015. This upward trend is very interesting, and future studies should be done which compare the data collected in the national survey of 2008 with data collected from a similar survey conducted at a national level nowadays which includes data retrieved from institutions. As institutions may represent a substantial portion of the ID population, including them in the sample collected was a good improvement to the 1999 survey and should be continued in the future.

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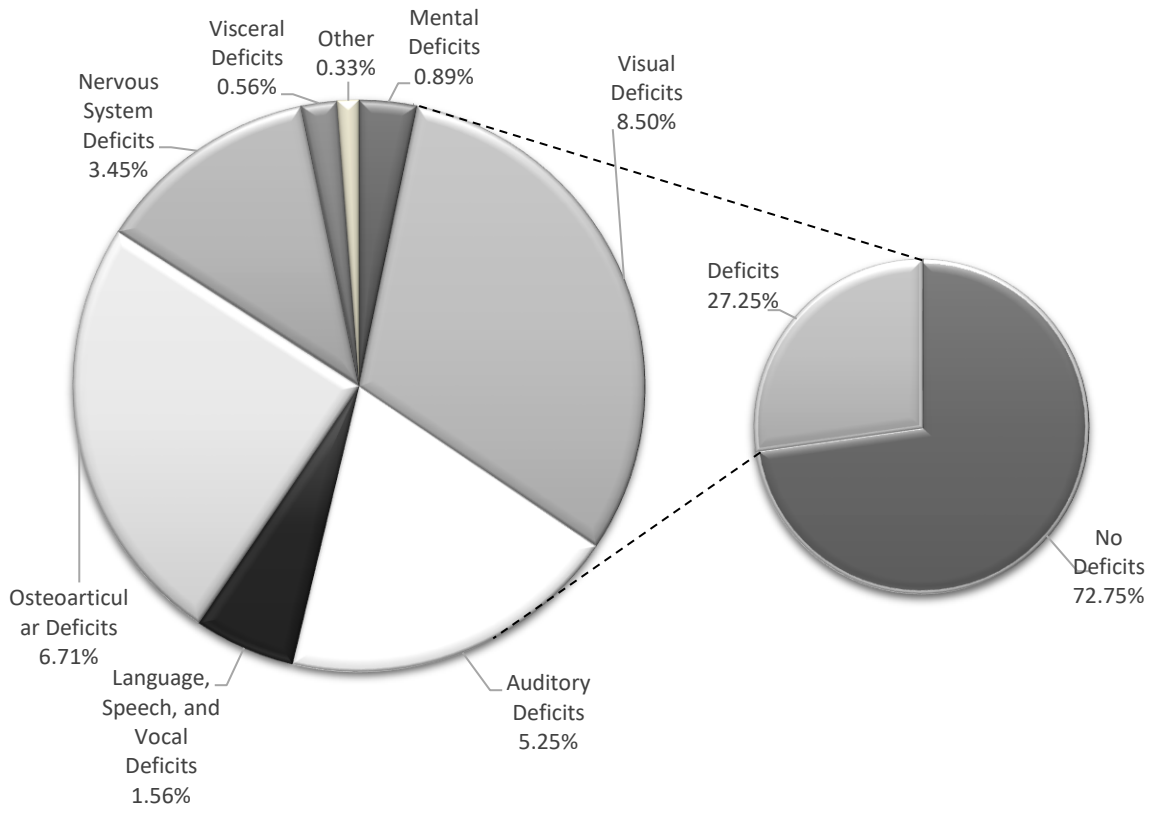
Appendix

Deficits by Systems in ID Population Older than 6 Years



Graph 2. The charts above represent the prevalence of a second, unrelated deficits in people over the age of six with intellectual disability. The chart on right shows the percentage of people with intellectual disability who also suffer from a separate deficit, while the chart on the left details the types of deficits that are suffered, as well as their rates.

Prevalence of Intellectual Disability, Down Syndrome, and Sex Ratio by Age Range (1999)													
Age	**ID N**	**ID %**	**Gen. N**	**Gen. %**	**Prev. ID %**	**Prev. ID CI- 95%**	**SR ID**	**SR Gen.**	**DS N**	**DS %**	**DS/ID %**	**DS/ID CI- 95%**	**SR DS**
0-9	17,365	11.22	3,786,355	9.65	0.46	0.43-0.49	0.76	1.06	5,086	15.84	29.29	28.62-29.97	0.73
6-9	**9,399**	**6.07**	**1,576,851**	**4.02**	**0.60**	**0.57-0.63**	**0.73**	**1.06**	**3,070**	**9.56**	**32.66**	**31.72-33.62**	**0.67**
10-19	26,783	17.30	4,861,577	12.39	0.55	0.52-0.58	1.41	1.05	5,321	16.57	19.87	19.40-20.35	1.08
20-29	36,460	23.55	6,494,367	16.55	0.56	0.53-0.59	1.53	1.04	8,205	25.55	22.50	22.07-22.93	1.06
30-39	36,835	23.80	6,248,419	15.92	0.59	0.56-0.62	1.64	1.02	7,769	24.20	21.09	20.68-21.51	1.20
40-49	20,924	13.52	5,151,574	13.13	0.41	0.38-0.43	1.33	0.99	3,525	10.98	16.85	16.35-17.36	1.41
50-59	8,383	5.42	4,309,249	10.98	0.19	0.18-0.21	1.34	0.97	1,797	5.60	21.43	20.56-22.32	0.65
60-69	5,070	3.28	3,989,858	10.17	0.13	0.11-0.14	0.97	0.89	95	0.30	1.88	1.54-2.29	-----
70-79	2,494	1.61	3,025,574	7.71	0.08	0.07-0.09	0.48	0.75	82	0.26	3.29	2.66-4.07	-----
≥ 80	482	0.31	1,380,039	3.52	0.03	0.03-0.04	-----	0.51	228	0.71	47.27	42.85-51.73	0.00
≥ 65	**5,391**	**3.48**	**6,434,523**	**16.39**	**0.08**	**0.07-0.09**	**-----**	**-----**	**405**	**1.26**	**7.51**	**6.84-8.24**	**-----**
Total	**154,796**	**100.00**	**39,247,012**	**100.00**	**0.39**	**0.37-0.42**	**1.34**	**0.96**	**32,108**	**100.00**	**20.74**	**20.54-20.94**	**1.03**

Table 4. Age: given in years; ID: Intellectual disability; Gen: General population of Spain; Prev: Prevalence; CI: Confidence interval; SR: Sex ratio; DS: Down syndrome

Prevalence of Intellectual Disability, Down Syndrome, and Sex Ratio by Age Range (2008)													
Age	**ID N**	**ID %**	**Gen. N**	**Gen. %**	**Prev. ID %**	**Prev. ID CI- 95%**	**SR ID**	**SR Gen.**	**DS N**	**DS %**	**DS/ID %**	**DS/ID CI- 95%**	**SR DS**
0-9	22,179	11.22	4,531,276	10.00	0.49	0.46-0.52	1.37	1.06	3,623	9.81	16.34	14.18-18.50	0.37
6-9	**8,088**	**4.09**	**1,722,239**	**3.80**	**0.47**	**0.44-0.50**	**1.30**	**1.05**	**979**	**2.65**	**12.10**	**10.20-14.01**	**0.26**
10-19	28,267	14.31	4,428,077	9.77	0.64	0.61-0.67	1.39	1.06	4,038	10.93	14.29	12.24-16.33	0.79
20-29	27,272	13.80	6,352,612	14.02	0.43	0.40-0.45	1.92	1.05	8,366	22.65	30.68	27.98-33.37	1.95
30-39	33,407	16.91	7,847,732	17.32	0.43	0.40-0.45	1.28	1.07	9,745	26.38	29.17	26.51-31.83	1.50
40-49	22,920	11.60	6,877,428	15.17	0.33	0.31-0.36	1.61	1.01	5,197	14.07	22.67	20.23-25.12	1.54
50-59	12,816	6.49	5,329,826	11.76	0.24	0.22-0.26	1.59	0.97	2,749	7.44	21.45	19.05-23.85	2.01
60-69	6,978	3.53	4,185,648	9.24	0.17	0.15-0.18	1.45	0.91	116	0.31	1.66	0.92-2.41	---
70-79	5,433	2.75	3,485,659	7.69	0.16	0.14-0.17	1.28	0.79	356	0.96	6.55	5.11-8.00	1.80
≥ 80	2,979	1.51	1,993,485	4.40	0.15	0.13-0.16	0.31	0.57	---	---	---	---	---
≥ 65	**20,042**	**10.14**	**7,358,726**	**16.24**	**0.27**	**0.25-0.29**	**---**	**---**	**356**	**0.96**	**1.78**	**1.00-2.55**	**---**
Institution	35,345	17.89	290,530	0.64	12.17	11.54-12.79	1.42	0.56	2,754	7.45	7.79	6.33-9.26	1.71
Total	**197,596**	**100.00**	**45,322,273**	**100.00**	**0.44**	**0.41-0.46**	**1.45**	**0.98**	**36,944**	**100.00**	**18.70**	**16.42-20.97**	**1.35**

Table 5. Age: given in years; ID: Intellectual disability; Gen: General population of Spain; Prev: Prevalence; CI: Confidence interval; SR: Sex ratio; DS: Down syndrome

Comparative Analysis 1999 and 2008				
	1999	**2008**	X^2	***p***
ID N	154,796	162,251		
Gen. N	39,247,012	45,322,273		
Prev. ID %	0.39	0.36	7.29	p < .01
DS N	32,108	34,190		
DS/ID %	20.74	21.29	0.021	p=0.88
% 0-64* ID	96.52	92.89		
% ≥65* ID	3.48	7.11		
Prev ID % 0-64	0.38	0.33		
Prev ID % ≥65	0.08	0.16		
% 0-39* DS	82.15	75.38		
% ≥40* DS	17.85	24.62		

Table 6. Statistical analysis of data from 1999 and 2008. ID: Intellectual disability; Gen: General population of Spain; Prev: Prevalence; DS: Down syndrome; *: Age range in years. In order to be considered significant, the p value must be less than 0.05.