EVERYONE IS SPECIAL IN THEIR OWN WAY

MILD INTELLECTUAL DISABILITY

ACKNOWLEDGMENTS

This project would not have been possible without the help and the support from a lot of people, that is why I want to thank everyone that helped me do this project and gave me support and encouragement when I was lost while doing the project.

First, I would like to thank Christy Kopp, my American host mother, who made me get interested in this topic, to let me focus the project on her daughter's case. Not only did she give me all the information that I needed in order to complete the project, but she helped me when I did not know something about the world of intellectual disabilities and special needs as well.

I would also want to thank my parents for supporting me and giving me advices during the research period. I also want to thank my aunt, who has been a really important emotional supporter and who helped me with the medical point of view, and to my sister to help me when I needed to doble check something that I had in different parts of the project.

And finally, I want to thank my English teacher, who has been the tutor of my project and has guided, advised and supported me, even when I was far away, and has helped me orientate parts of the project that I did not know how to orientate.

Without all this people, I would not have been able to pull this project through.

RESUM

A partir de l’interès per les discapacitats intel·lectuals, que pateix entre un 1 i un 3 per cent de la població i que són les més comunes quan es fa referència a les discapacitats de desenvolupament, s’ha plantejat conèixer el màxim d’informació possible sobre la discapacitat intel·lectual MILD. Els objectius d’aquest treball són: aprendre sobre les discapacitats intel·lectuals; entendre la diferència entre discapacitat intel·lectual i trastorn de tipus mental o emocional; donar visibilitat a aquestes discapacitats; aportar més coneixement sobre aquestes; comparar el coneixement que tenen els americans i els catalans sobre aquestes discapacitats (es parteix d’una hipòtesi principal que és la següent: als Estats Units d'Amèrica hi ha més coneixement i visibilitat); i, finalment, crear un pla de treball per fer amb una persona que pateix la discapacitat intel·lectual MILD. Per assolir els objectius, s’ha dut a terme una cerca documental, a partir de documents de la Quincy, una noia que pateix la discapacitat en qüestió; pàgines web; llibres; i un seguit d'enquestes i entrevistes. Aquesta investigació ha permès arribar a unes conclusions: es pot afirmar que no hi ha prou visibilitat ni coneixement sobre aquestes discapacitats ni a Catalunya ni als Estats Units; també s’ha vist que hi ha moltes persones que confonen les discapacitats intel·lectuals amb els trastorns mentals i emocionals; i, per acabar, s’han descobert i treballat les dificultats amb què conviuen les persones amb discapacitats intel·lectuals.

RESUMEN

¿Cómo es vivir en el cuerpo de una persona de 18 años, pero tener la mentalidad de 9 años? Entre un 1% y un 3% de la población sufre discapacidades intelectuales. Estas son las más comunes al hablar de discapacidades del desarrollo y son una condición de por vida. La discapacidad intelectual MILD es la que se trabaja en este proyecto a raíz de Quincy, una joven que sufre esta discapacidad. A partir de aquí, los objetivos de mi trabajo han sido: aprender sobre las discapacidades intelectuales; entender la diferencia entre discapacidad intelectual y trastornos de tipo mental o emocional; dar visibilidad a estas discapacidades; aportar más conocimiento sobre ellas; comparar el conocimiento que tienen los americanos y los catalanes sobre estas discapacidades (mi hipótesis era que en los Estados Unidos de América habría más conocimiento y visibilidad); y, finalmente, crear un plan de trabajo para llevar a cabo con una persona que sufre una discapacidad intelectual. Para alcanzar los objetivos, he realizado una búsqueda documental a partir de documentos de Quincy; páginas web; libros; y de un seguido de encuestas y entrevistas. Finalmente, habiendo realizado esta investigación, he llegado a la conclusión de que no hay suficiente visibilidad y conocimiento sobre estas discapacidades ni en Cataluña ni en Estados Unidos; también he constatado que hay muchas personas que confunden las discapacidades intelectuales con los trastornos mentales y emocionales; y, para finalizar, he descubierto y trabajado las dificultades con las que conviven las personas con discapacidades intelectuales.

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INTRODUCTION

How is living in the body of an 18 years old but having the mentality of a 9 years old? How do the family of that person live their everyday life while living with the disability? These were some of the questions that I had in my mind one year and a half ago, when I received a message that told me I was placed with a host family that had a member with an intellectual disability.

Everyone is special in their own way is the name of the project that wants to give visibility and information about intellectual disabilities, and it is focused on the disability known as MILD intellectual disability or Mental retardation - high functioning.

The reason I chose intellectual disabilities as the topic of my project is because when they told me that one of the members of my host family suffered from an intellectual disability, I did not know what to think, I had no idea about how the life of those people was and due to that fact I thought it was an awesome idea to do this project about intellectual disabilities because there needs to be more information and visibility about these disabilities and how the life of the people suffering from them and their families are.

In 2021, I spent the school year in the United States of America as an exchange student. During that year, I stayed with a host family where I had two host sisters. One of my host sisters suffers from an intellectual disability, and I had never been in touch with this type of disabilities before, it was a really interesting experience, I learned a lot and saw very different aspects of life. During that year, I realized that there was much more knowledge and visibility on these disabilities in the United States than in Spain, where there is not enough knowledge or visibility.

This project is based on two parts, the first one is the Theoretical part, where there is all the information needed to understand what intellectual disabilities are, the types, and the differences and common aspects among all the different intellectual disabilities, and then there is the more detailed information about the intellectual disability I focused my project on, which is the one that my host sister suffers from. The second part is the Practical part where I included all the information that I have acquired and I created a weekly plan for a person suffering from a MILD intellectual disability. I was also really interested in seeing how much difference of knowledge about intellectual disabilities there is between the United States and Catalonia, so I did a comparison of the knowledge that the people of Catalonia and the people of the United States have about intellectual disabilities, by using questionnaires that I created, to see if my initial hypothesis is true or it is not.

My initial hypothesis was that in the United States there is more knowledge and visibility of these disabilities than in Spain and there are also more organizations that prepare fun activities for the people suffering from intellectual disabilities.

When I began this project, my main objective was to give visibility about Intellectual Disabilities to the people of my surroundings, but while doing it I have seen that I actually had more objectives than that main one, another objective, was to learn more about the topic that kept me really interested while in the United States, I wanted to gain knowledge about the disability that my host sister has, and understand the difference between intellectual disabilities and emotional disorder, which lots of people confuse. The objectives of the practical part were to compare the knowledge of Catalan and American people, and to be able to create a plan as the staff member for a person with MILD intellectual disability.

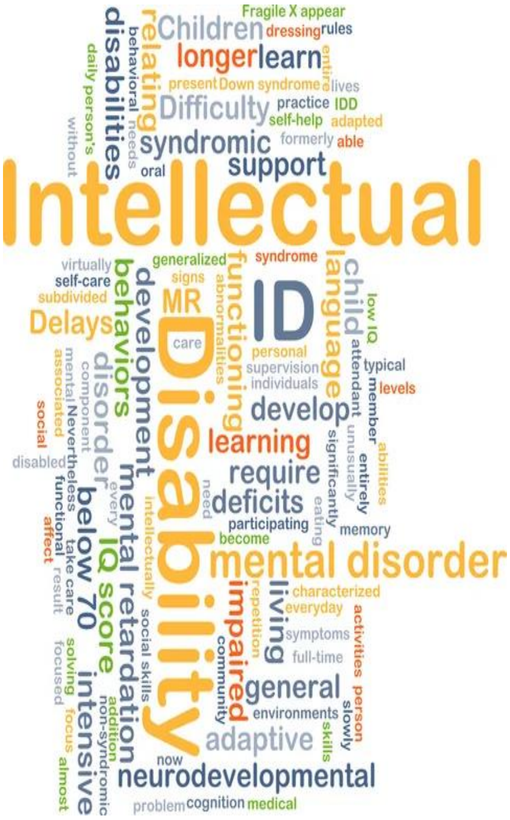
To be able to do this project, I looked up lots of information on different websites, asking questions and receiving information from people that have a family member suffering from intellectual disabilities, I also had lots of information already collected from my own experience. I increased my knowledge about this topic by reading books that helped me understand the phases that all these people go through and why that happens. I also had lots of medical documents from my host sister that my host mother let me use for this project, and that helped me understand what goes on in the school district, and medical life of a person that is intellectually disabled, and how doctors qualify the different levels.

- This project has been written in American English. The information used makes reference to the United States of America. -

THEORETICAL PART

1. INTELLECTUAL DISABILITIES

Most people think that there are not many people that suffer from intellectual disabilities, but the truth is, in the United States of America, there are approximately 6.5 million people that have an intellectual disability and also, approximately from 1 to 3 percent of the global population suffers from an intellectual disability which, if it is looked in numbers, sums up to 200 million people.



Picture 1: Intellectual disability

Intellectual disability is the most common developmental disability and it is a lifelong condition, which can be due to health problems, genetic conditions, environmental factors and problems during pregnancy and birth.

It is also known as ID, and it is a term that is used when there are some important limitations in a person's cognitive functioning and skills, these problems or limitations involve problems with general mental abilities and affect functioning in two areas: intellectual functioning, which is also known as intelligence, and includes learning, problem solving, judgment and it is measured by taking an IQ. The second area is adaptive functioning, which includes activities of daily life, and there are three different categories:

- Conceptual skills, which include language, concepts as money, time and numbers and also self-direction skills.
- Practical skills, which consist of activities of daily living, like personal care, occupational skills, health care, transportation, routines, schedules, safety, how to use money, or how to use a telephone.

- Social skills, which cover the part of interpersonal skills, social responsibility, self-esteem, how to solve social problems, the ability to follow rules and obey laws and be able to avoid being victimized.

Suffering from these limitations can cause a child to develop and learn more slowly or in a different way from what it is known as in an average developing child, meaning that those kids with intellectual disabilities are limited to learn at an expected level and it might be harder for them to let others know what they want or need. That is because their brain has not developed properly or has been injured in some way.

These disabilities known as intellectual disabilities can happen any time before a child turns 22 years old and even before the child’s birth.

Suffering from an intellectual disability does not mean that the person is never going to have and independent life. It depends on what type of disability the person suffers that it could be possible for that person to end up having partial or even a full independent life.

These disabilities may also be associated with other disorders such as emotional and behavioral disorders, when a child with an intellectual disability realizes or feels that he or she is behind other children of their age, that child can become frustrated, anxious or have bad behaviors to get the attention of others. These feelings could improve by setting appropriate expectations, limits and other measures that will help them handle the stresses of growing up.

When talking about intellectual disabilities, there are lots of different disabilities and illnesses included in this term.

Some people confuse intellectual disabilities with mental illnesses such as depression, which has nothing to do with it. An intellectual disability rates the intellect that the person has, as a difference, a mental illness does not necessary mean someone has issues with intellect, it is a broad term of cognitive issues and those can usually be cured, not like intellectual disabilities that have no cure. Some examples of mental illnesses are: depression, anxiety, dementia, bipolarity…

2. TERMINOLOGY

aaidd
American Association
on Intellectual and
Developmental Disabilities

Picture 2: AAIDD

In the past, for many decades, the medical establishment and the general public unkindly referred to people suffering from these disabilities as “feeble minded”, “moron” or “idiot”. It was in the 1960s when the American Association of Intellectual and Developmental Disabilities (AAIDD) and some lawmakers adopted the term “mentally retarded” as the new way to name people with these disabilities because, at the time, the experts considered that term to be more sensitive. Even the change they did, families of individuals that suffered those types of disabilities thought it was still disrespectful and brought negative attitudes and negative connotations, being offensive to many people. They could also turn up to create misunderstandings about the nature of the disorder, so those families with lawyers continued fighting for the replacement and improvement of the term used for these cases.

The term that is used nowadays is “intellectual disability”. This term came out because of Rosa’s Law[1]. Even though it was not changed in the Federal Register until January 28th, 2013 when the term “mental retardation” was replaced with “intellectual disability” in the Listing of Impairments used to evaluate claims that involve mental disorders in adults and children. That

Picture 3: Rosa’s Family

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[1] Rosa’s Law: is the law that in 2010 removed the terms “mental retardation” and “mentally retarded” from federal Health, education and labor policy and replaces them with the term that is used nowadays “intellectual disability”.

"Respect, value, and dignity—everyone deserves to be treated this way, including people with intellectual disabilities," words said by Dr. Timothy P. Shriver, who is a Chairman and CEO of Special Olympics, the world’s largest movement dedicated to promoting respect and human dignity for people with intellectual disabilities said after Rosa’s Law was approved by the House of Representatives and the Senate.

change reflected the widespread adoption of the term by Congress, governmental agencies and public and private organizations. The final rule was not effective until September 3rd, 2013.

3. HISTORY OF INTELLECTUAL DISABILITIES

Some of the very first references to intellectual disability found date back to the ancient Egyptians, where this concept was mentioned in the Papyrus of Thebes[2] over 3500 years ago. The ancient Romans and Greeks viewed the children that were born with intellectual disabilities as a result of the anger of the Gods. As a result, many of these children were simply left to die in the wild, even though exceptions did occur, like in the case the child was born in a wealthy Roman family, they had some legal rights and sometimes even guardians.

In the medieval period, there was not any state provision for people with disabilities. Most of the people suffering from this kind of disability lived and worked in their own communities and they were usually supported by family and friends. It was not usual to get support by their town or village but it could happen sometimes when the person suffering the intellectual disability was not able to work.

Monks and nuns were the ones who usually took care of the people suffering from an intellectual disability. They would take care of them as their Christian duty. Those monks and nuns would base their teaching on the church´s teachings. They had two sets of tasks to make people with disabilities do during the day known as “comfortable works”, which included feeding, clothing and housing the poor, visiting them when they were in prison or sick, offering drink to the thirsty and burial. And the other set of works known as “spiritual works” included counsel and comfort for the sick people.

During this period, a network of hospitals in or near religious establishments began to emerge. We find the possible first world´s mental institution in England which was originally the Bethlehem hospital in the city of London. Furthermore,

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[2] Thebes is a province located along the Nile River. It takes the name of the capital of Egypt during the reign of Pharaoh Merenre.

during that time there were almshouses that provided a supportive place to the disabled and elderly to live.
We also find that, eventually, people with intellectual disabilities were employed as jesters whose only purpose was to entertain the upper class.

Thomas Willis[3] provided the first description of intellectual disability in the 17th century. He nominated intellectual disabilities as a disease since he believed that what caused those disabilities were structural problems in the brain. According to Willis, the anatomical problems that caused that person to have a disability could either be an inborn condition or acquired later in life.

In the 18th and 19th centuries, housing and care moved away from families and towards an asylum model[4].

Picture 4: Asylum model

People were placed by their families to a house in a large professional institution, many of those were self-sufficient as they made the residents do the different tasks and labors. Some of these institutions provided a very basic level of education, but most continued to focus solely on the provision of basic needs of food, clothing, and shelter. Conditions in those kinds of institutions varied widely, but the support provided was normally non-individualized. Still during the

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[3] Thomas Willis was a British doctor who had a really important role in the history of anatomy, physiology, neurology and psychiatry, and he was also a pioneer in his neuroanatomical research.

[4] The asylum model is a house where multiple people live together, with care workers that help they in their everyday life.

19th century, people suffering from intellectual disabilities were still referred to as *idiots, feebleminded or retarded*. During that time, people like Itard[5], Guggenbuhl[6], Howe[7] and Seguin[8] were influential individuals who led the beginning of the concept of care and education provision for people with intellectual disability.

The 20th century has been the century of changes in the world of intellectual disabilities. During the early 20th century, many countries were poor or were going through a hard time economically and social conditions were difficult. That caused fear and stereotyping by the general public towards people suffering from intellectual disabilities and that had a huge impact on the education of individuals with intellectual disabilities. Instead of educating them so they could live and adapt well in the community, they used the education withing custodial institutions to sustain the institute and not to teach new skills. That gave rise to the isolation from society of people with intellectual disabilities. The mid-20th century was the time where the life of all those people suffering from intellectual disabilities started to change. It was all because of Dr. Wolf Wolfensberger[9], who thought towards the education and care of people suffering from intellectual disabilities and made it happen by advocating for the value in the lives of people with intellectual disabilities. "*Patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society*" is the principle known as *"Principle of Normalisation"*, which was created by Dr. Wolf Wolfensberger, who was also

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[5] Itard was a doctor who is known for working with Victor d'Aveyron, also known as "the wild child of Avairon". His contribution in the field of education is known for facilitating the educability of the mentally deficient.

[6] Guggenbühl was a Swiss psychiatrist and analytical psychologist.

[7] Dr. Samuel Gridley Howe was an American doctor who was involved in many social causes and he was also concerned about the conditions of persons with intellectual disabilities.

[8] Eduardo Séguin was a doctor who worked with intellectual disabled children in France and in the United States

[9] Dr. Wolf Wolfensberger was a German-American who fought for the normalization and social valorization in America and in Europe of people with disabilities.

the creator of Citizen Advocacy[10] and Social Role Valorisation[11] that was centralized on speaking out and speaking up for those people who were more vulnerable in society.

Nowadays, there are lots of movements that fight for the normalization and effective therapies for people with intellectual disabilities. The social care provision for people suffering from intellectual disabilities has improved and as a result, their overall health and wellbeing has improved as well. However, as this is the beginning and the first time in history people with intellectual disabilities can live longer into old age, there is very little knowledge of their ageing experiences and the way they age. It is known that they get older age conditions at a younger age and this implements a mortality rate average 20 years younger than non-disabled people.

4. INTELLECTUAL DISABILITY'S DIAGNOSES

The condition of intellectual disabilities normally originates during the developmental period of the person. The ages that mark an ending point to this period are between 18 and 21 years old, meaning that the disability can show up until the age of 21, although in most of the cases, people who suffer from these disabilities are already born with them.

According to the American Association of Intellectual and Developmental Disabilities, an individual suffers from an intellectual disability if he or she meets the following two criteria:

4.1 INTELLECTUAL FUNCTIONING

Intellectual functioning, also known as intelligence, is what refers to the general mental capacity, such as academic learning, reasoning, problem solving, planning, abstract thinking, judgment, and learning from experience.

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[10] Citizen Advocacy is used for increasing inclusion, maximizing autonomy and safeguarding against violence or exploitation.

[11] Social Role Valorisation is the theoretical basis to make people understand the segregation and unconscious perceptions of people with disability.

There are multiple ways to measure intellectual functioning but the one that is used the most is an IQ test. The average IQ score is between 85 and 115. Knowing that, when an IQ test score is around 70 or as high as 75 means that the patient suffers from a significant limitation in intellectual functioning, which concludes that the patient is suffering some type of intellectual disability.

4.2 ADAPTIVE BEHAVIORS OR FUNCTIONING

When talking about adaptive behaviors, we are talking about the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

The Conceptual skills are based on the language and literacy, money, time, and number concepts and also includes self-direction.

The Social skills are based on interpersonal skills, social responsibility, self-esteem, gullibility, social problem solving, and the ability to follow rules or obey the laws and to avoid being victimized.

The Practical skills are daily living activities such as, personal care, occupational skills, healthcare, travel and transportation, schedules or routines, safety, use of money and use of the telephone.

There are other tests like Standardized tests, which are tests that require all the people who take it to answer the same questions, in the same way and that is scored in a consistent manner that makes possible to compare it among the different groups that have taken the test, and those can also be used to determine limitations in adaptive behavior.

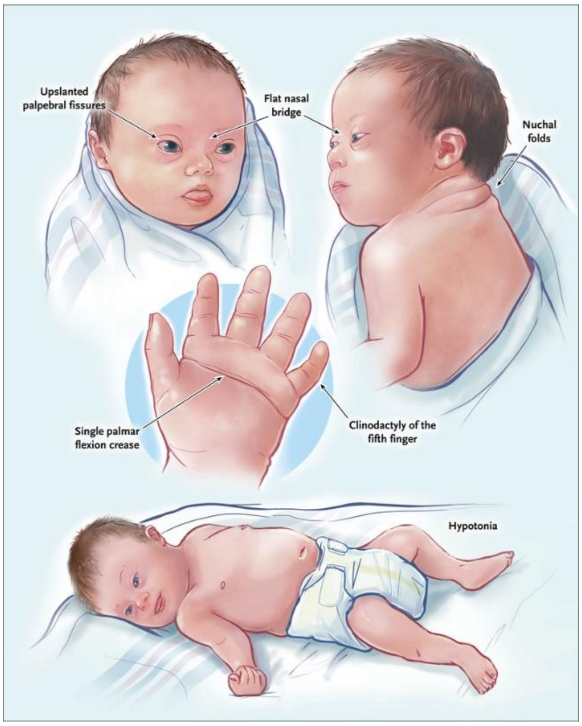
If there are significant limitations in two or more adaptive areas, which are made up of skills needed to live, work and play in the community, it means we should be talking about intellectual disabilities.

5. MOST COMMON INTELLECTUAL DISABILITIES

Even though there are lots of different intellectual disabilities, and most of these disabilities do not have an actual diagnose and are just known by the severity because there is not enough information about them, there are 5 intellectual disabilities that are the most typical ones and there is enough information to have an actual diagnose. It is true that a person can suffer more than one intellectual disability at a time.

These disabilities are Down's Syndrome, Fragile X Syndrome, Fetal Alcohol Syndrome, Prader-Willi Syndrome and Autism.

5.1 DOWN'S SYNDROME



Picture 5: Down syndrome physical characteristics

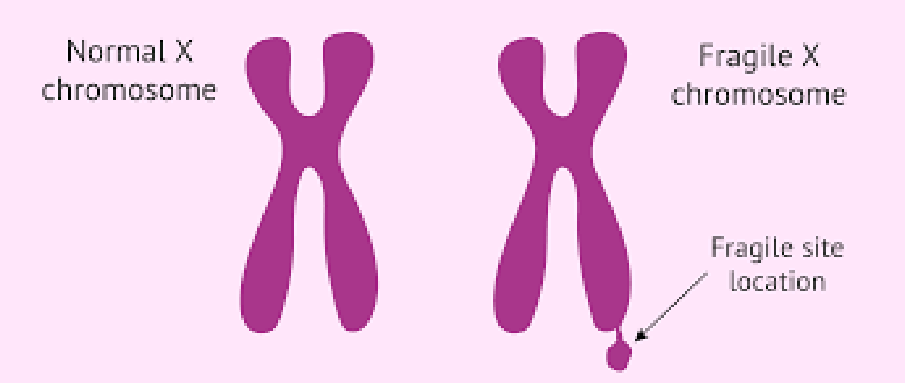
Down's Syndrome is an intellectual disability that happens because of having an extra chromosome 21 in the DNA, this extra copy can be full or partial. Having this alteration on the DNA can be the cause of mild to moderate intellectual disabilities in children. The development of children suffering from Down Syndrome is affected and they reach the key developmental stages much later than an average child. Slow learning, short attention span, impulsive behavior, poor judgment and delayed language or speech development are the common symptoms of Down Syndrome and suffering this disability also affects the muscle tone, which is poor in these children and that causes them to take much longer on learning how to do some easy and daily living movements such as turning over, walking, standing and sitting. In this disability, the physical appearance of the people suffering from is not as an average person, they have some physical characteristics such as flattened facial profile and nose, small head, small ears and small mouth, they can also suffer from some other health factors such as heart abnormalities, hearing loss, vision problems and respiratory conditions.

Thanks to the increase of research and technology in the area these past years, nowadays, the lifespan of individuals with Down Syndrome has increased and their life is a litter better than what it was in the past.

5.2 FRAGILE X SYNDROME

Fragile X Syndrome is a developmental disability and also an intellectual disability and it is one of the most commonly known causes of inherited disability. It consists of a genetic disorder that is a result of a mutation in the X chromosome.

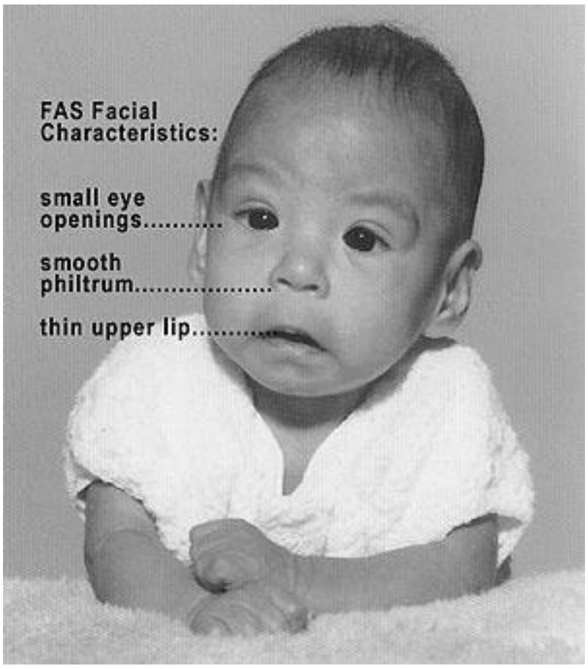
The affections that it has on the person are developmental, which consist of learning and behavior, but it can also affect physical appearance, communication skills and sensitivity to the individual's light and noise, however, the severity can be very varied. What is more, boys are usually more affected than girls by this disability, it affects around 1 in 3.600 boys and between 1 in 4.000 to 6.000 girls. People suffering from this disability do not have the same signs and symptoms, however they do have some common signs like problems with the speech and language, attention disorders problems and it also affects hyperactivity, anxiety developmental delay, problems while processing sensory information, they are aggressive from the sudden, and they have lots of problems when making eye contact with others.



Picture 6: Fragile X Syndrome

5.3 FETAL ALCOHOL SPECTRUM DISORDER

Fetal Alcohol Spectrum Disorder is caused by exposure to alcohol of the unborn fetus during pregnancy, it happens when the pregnant women decide to drink alcohol that crosses the placenta from the mother's bloodstream into the baby's and expose their children to the risk of suffering this disability. Depending on the level of exposure that the child is exposed to, the severity of the disability is bigger or lower. Large quantities of alcohol during pregnancy increase the risk of severe symptoms in their children. The most common symptoms found in children that suffer from Fetal Alcohol Syndrome are facial, limb and joints deformities, poor memory and judgment, poor social skills, sensory difficulties which include hearing and vision, heart problems and they can also have some heart defects, behavioral problems and slow physical growth, they also suffer from learning disabilities. Most of the symptoms of the disability can be reversed if there is an early intervention, this means do surgeries such as heart surgeries.



Picture 7: Fetal Alcohol Spectrum Disorder physical characteristics

Many cases are often misdiagnosed as autism or ADHD as they can have similarities. That is the reason why the World Health Organization recommends that mothers-to-be, or those women planning on getting pregnant, should completely avoid drinking alcohol.

5.4 PRADER-WILLI SYNDROME

Prader-Willi Syndrome is a genetic disorder which is due to an abnormality on the chromosome 15. Babies born with this disability are poor feeders at infancy, even though the feeding habit changes at the age of two, when the kid's hunger becomes insatiable. They have an urge to eat because their brain, specifically the hypothalamus[12], will not tell them that they are full, so they are always feeling hungry. All these problems with hunger and eating lead to weight problems such as diabetes and obesity. Some of the symptoms that people suffering from this disability have are problem-solving, language, and math difficulties, poor muscle tone, diabetes or obesity, short stature, hyperphagia[13] emotional difficulties, skin picking, hormone deficiencies and also sleep issues like sleep apnea[14].

When the children are below the age of two, they tend to exhibit developmental delays, weal cry, feeding difficulties, and also undernourishment and then during teenage years, when suffering from this disability, the teens suffer a delayed puberty, and the risk of scoliosis increases, and it also makes social skill deficiencies increase. The good part is that early age interventions can help manage the symptoms of Prader-Willi, basically in the areas of the intellectual ability of the child.

5.5 AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder is a disability caused by differences in the brain. Even though most of the causes are not yet known, scientists believe there are multiple causes of autism spectrum disorder, also known as ASD, and these causes act together to change the most common ways people develop. People with ASD can have different ways of behavior, communication, interaction and they also learn in a different way from most other people. However, the abilities that people with ASD can vary significantly, some people may have advanced

Picture 8: Max

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[12] The hypothalamus is a part of the bran that has a variety of functions. One of the most important functions is to link the nervous System to the endocrine System via de pituitary gland.

[13] Hyperphagia is an abnormally increased appetite that is frequently associated with injuries to the hypothalamus.

[14] Untreated sleep apnea causes breathing to stop repeatedly during sleep, causing loud snoring and daytime tiredness.

conversation skills while others may be nonverbal. Autism can begin before the age of three and can last throughout a person's life, although some symptoms can improve over time, some people gain new skills and meet developmental milestones until around 18 to 24 months of age and then they stop gaining new skills or lose the ones that they once had. Some of the signs that people with ASD often have are problems interacting and communicating with other people, and they have restricted or repetitive behaviors. ASD can also affect the way the people suffering from it learn, move or pay attention, but not everyone having different ways of learning, moving or paying attention have Autism.

Intellectual disabilities are not always classified by a specific name or because of a specific reason that causes the disability, IDs can also be classified by the severity of the disability. There are some disabilities that can be completely different between two people but they are called the same because they are classified by the severity. This can be due to the lack of information about these disabilities that scientists and doctors have. This fact does not allow to put an actual name to the disability.

There are four different levels of severity that the disabilities are classified by, these levels are Mild, Moderate, Severe and Profound. All the information about these severity levels is in the chard below.

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)	AAIDD Criteria (severity classified on the basis of intensity of support needed)	SSI Listings Criteria (The SSI listings do not specify severity levels, but indicate different standards for meeting or equaling listing level severity.)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.	Intermittent support needed during transitions or periods of uncertainty.	IQ of 60 through 70 *and* a physical or other mental impairment imposing an additional and significant limitation of function
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.	Limited support needed in daily situations.	A valid verbal, performance, or full-scale IQ of 59 or less
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.	Extensive support needed for daily activities.	A valid verbal, performance, or full-scale IQ of 59 or less
Profound	1.5%	IQ <20	Requires 24-hour care.	Pervasive support needed for every aspect of daily routines.	A valid verbal, performance, or full-scale IQ of 59 or less

Chard 1: Severity Categories of Intellectual Disabilities

The evaluation of the level of severity is not defined in terms of deficits, the AAIDD evaluates the severity of ID with the Supports Intensity Scale (SIS. This focuses on the types and intensities of supports needed to enable an individual to lead a normal and independent life, and it is based on the support needs of an individual across 49 life activities. These activities are divided into six categories which are: home living, community living, life-long learning, employment, health and safety, and social activities.

This project is focused on the MILD intellectual disability.

6. MOST COMMON CAUSES

Each intellectual disability has its causes but there are some causes that most of this type of disability have in common. These are genetic conditions which can be caused by abnormal genes that the child inherited from their parents, or also errors when the genes combined, like Down syndrome and Fragile X syndrome.

Another factor that can affect the developing of intellectual disabilities are complications during the pregnancy. If the baby is not properly developed when inside the mother’s body, it can produce problems that can affect the child’s health and cause an intellectual disability. An example of this case is when the mother drinks alcohol during the pregnancy, which can end up carrying out problems with cell division and the way in which the baby’s cells divide, causing an intellectual disability.

Problems during birth can also influence. If there are complications during labor or birth, such as a baby not getting enough oxygen, can increase the possibilities of the baby to suffer from an intellectual disability.

And the last most common cause can be called physical and it is due because of a disease or toxic exposure, such as whooping cough or meningitis, which can bring up intellectual disabilities. Moreover, they can also be caused by extreme malnutrition, not getting appropriate medical care or being exposed to poisons like mercury.

Brain malformations can be another cause but it is not necessary for the malformation to happen before the child's birth, as intellectual disabilities can also be the result of an injury or accident that affects your brain once the person is older.

7. RELATED CONDITIONS AND EFFECTS

Intellectual disability frequently co-occurs with other conditions that the person suffers and that are related conditions. These conditions can be developmental, physical, medical, and psychiatric. It is normally really hard and challenging to identify these illnesses because the person affected has often limited communication skills.

These related conditions commonly include anxiety and depression disorders, autism spectrum disorder, defects of the heard, eyes, digestive trach and other organs, epilepsy, which is a neurological disorder that causes seizures due to the effects of the brain activity, and also impulse control disorder. It can also include bipolar disorders, impulse control disorders, major neurocognitive disorder, self-injuries and stereotypical movement disorder.

There are also some effects that intellectual disabilities can have on the people suffering from them, and even though every person suffering from an intellectual disability is unique, there are some common effects that can affect every one of them, which include the requirement of special teaching and training to be able to learn, the need of support to solve everyday problems, the inability to establish interpersonal relations or feel dependent of others, difficulties in finding, and maintaining gainful employment, difficulties functioning on a daily basis. They are not able to leave on their own and they also often have suicidal thoughts and behaviors because they feel like they do not fit in and they want to be treated as everyone else.

8. MILD INTELLECTUAL DISABILITY: MENTAL RETARDATION – HIGH FUNCTIONING

Intellectual disabilities occur approximately to 1.5 percent of the population and most of the people that are diagnosed with an intellectual disability suffer from the MILD Intellectual Disability. The exact number is the 85 per cent of the people that suffer from an intellectual disability fall into the “mild” category.

People with MILD ID are slower in all areas of conceptual development and social and daily living skills, which means that they need help all the time during the day. This does not mean that they are never going to learn these skills, they can learn practical life skills, which allow them to do their everyday life with minimal levels of support. People with this disability may also often have ADHD.

Individuals that suffer from MILD can take care of themselves, travel to familiar places in their community, and learn basic skills related to safety and health, but it is going to be really hard for them to learn all these skills and their self-care requires moderate support.

8.1 CAUSE OF THE DISABILITY

Possible or certain causes can be categorized according to the time the brain injury or disorder originally arose, which happens in all neurodevelopmental disorders. There is usually a distinction between three phases where the injury or disorder could have happened. These three phases are the prenatal period, which is the period before the birth of the child, the perinatal period, which is the first week and it also includes the birth itself, and the postnatal period, where the injury or disorder occurs after the birth of the

Picture 9: Quincy’s brain tests

Picture 10: Quincy’s brain tests

child.

As far as the prenatal causes is regarded, genetic factors are the dominant causes and include inherited conditions and "*de novo*", which are new mutations, and these causes are the ones that cause a large number of known syndromes[15]. These genetic syndromes can cause mild intellectual disability. Thanks to CGH[16], which means "comparison genomic hybridization", doctors are capable of detecting very small genetic abnormalities, which could be deletions or duplications, and makes the improvement of genetic diagnostics possible.

Furthermore, there are the perinatal causes, which can be due to complications during birth or during the first week of life of the child. However, there are many children that suffer from a mild intellectual disability for whom there is not an exact medical cause, the medical cause is much more frequently identified when the intellectual disability is more severe.

Mild intellectual disability can sometimes also be an expression of the variation in human abilities and aptitudes which are demanded by society.

8.2 SYMPTOMS

Mild intellectual disability involves deficits and difficulties in aspects such are thinking or learning, which means that the person who suffers from this disability recognizes and understands their surroundings in a different and more concrete way, and that makes it harder for them to interpret and deal with abstract words, symbols or descriptions among other things. These difficulties delay their learning, especially their ability to absorb the theoretical knowledge, which makes school much more difficult for them.

The delay and deficits in their theoretical and abstract thinking affects their adaptive functioning, so most people with mild intellectual disability need support from staff members or family members throughout their lives just to get

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[15] Syndrome, refers to several signs and symptoms that occurred simultaneously and are clinically observable which indicate an underlying medical condition.

[16] Comparative genomic hybridization (CGH) is a method that can be used on DNA extracted from routinely fixed tissue to assess the entire genome for the presence of changes in DNA copy number.

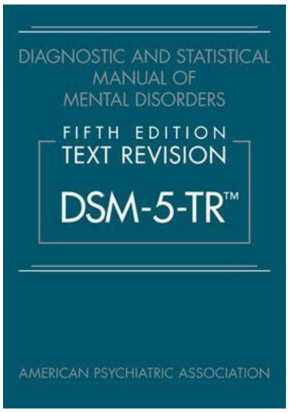
through their everyday life. For them, adapting and learning how to adapt to the adult world can be extremally difficult and challenging, these challenges could be managing their job, home and finances. Adaptive functioning is usually divided into three domains:

- Cognitive, which includes reading, writing arithmetic and other concepts needed for basic life such as time and money. It is really important to make them understand this concept and it is going to take them much longer than in a normal situation to learn those concepts and get used to using them in the correct circumstances.
- Social, the delays in social functioning makes it genuinely hard for them to have social relationships in an age-appropriate way; in fact, it is due to their impaired communication skills that they have difficulties understanding signals from peers and poor social judgment, which might lead them to be manipulated by others.
- Practical functioning limitations can lead them to an inability to handle daily routines such as taking care of themselves, taking care of their house, or making decisions about legal and health-related issues, which makes it impossible for them to have the control of their everyday life. As a result, they need support in every routine or activity that they want to do.

When some of these events are happening to the child, the parents realize that something is not working as it should. Besides, most of the parents realize that something is wrong if they have another child, then they see that one child learns how to do the basic things as walking or talking much earlier than the other and that makes them start to think about what is going on. They need a diagnosis.

People that suffer from a MILD intellectual disability also have some concurrent cognitive difficulties, and that is a common aspect among individuals with mild ID. These cognitive difficulties, often related to concentration, motor control, language and communication, social interaction, sight, and hearing, present additional problems that need to be recognized in each one of the cases.

8.3 DIAGNOSES

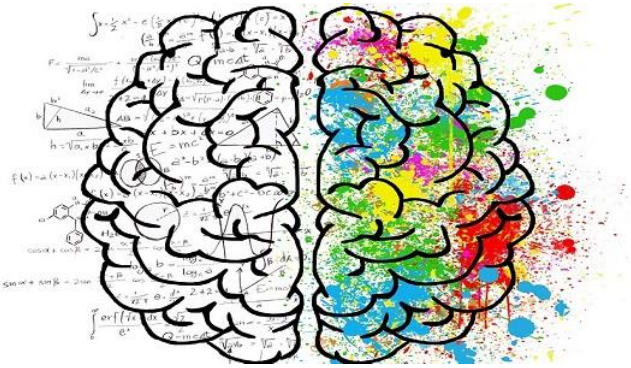


Picture 11: DSM-5-TR

Mild intellectual disability is defined by three criteria according to DSM-5[17]. These three criteria include point A, which talks about the deficits in intellectual functioning, problem solving skills, abstract thinking and theoretical learning; point B, which is based on the deficits in adaptive functioning, cognitive, social and practical skills in everyday life; and last, point C, which talks about the difficulties that must have originated during the individual's developmental periods.

A. Deficits in intellectual functioning; problem solving skills, abstract thinking and theoretical learning.

In these criteria, the intellectual functioning is assessed by testing the individual's cognitive functions, using standardized psychometric test instruments, which are automated, structured frameworks to ensure an unbiased evaluation of psychological characteristics, such as personality, creativity, intelligence, motivation, and values. Common assessment tools include Leiter, which is a test designed to evaluate cognitive functions in children and adolescents between the ages of 2 to 20. The battery measures nonverbal intelligence in fluid reasoning and visualization, as well as evaluation of visuospatial memory and attention. The Wechsler scales, which is the most frequently used and it is based on the use of intelligence tests to evaluate the level of cognitive functioning in individuals with psychiatric illness or brain injury. The Snijders-Oomen (SON-R) which are one hour



Picture 12: Psychometric tools

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[17] DSM-5 is the name of a book that contains the most up-to-date criteria for diagnosing mental disorders.

long, nonverbal tests that are especially appropriate for evaluating individuals with problems or handicaps in the area of language and speech development and communication. These tests are special because they are classified as child friendly because of their adaptive nature and feedback that participants receive.

B. Deficits in adaptive functioning, cognitive, social and practical skills in everyday life.

In this case, adaptive functioning is assessed by collecting information about the child's development and functioning from parents or guardians, child health care services and school, including school health care services, and in the case of adults, other loved ones. Adaptive functioning bounds skills needed in everyday life, so part of the evaluation involves determining how much support the patient requires either from their family member or actual formed staff. Scoring scales are often used to supplement and solidify the evaluation process and in such cases the Vineland Adaptive Behavior Scales, which is based on a standardized evaluating tool that utilizes semi-structured interview to measure adaptive behavior and support the diagnosis of intellectual and developmental disabilities, or ABAS (Adaptive Behavior Assessment Scales) are the most commonly used.

C. Difficulties that must have originated during the individual's developmental periods.

Any diagnoses of intellectual disability ultimately hinge on these three criteria. One must also determine whether the cognitive and adaptive deficits might be due to some other disorder, for example major attention deficits or language difficulties, rather than the result of the intellectual disability, because this result could be affected by other aspects. It is important to know that when diagnosing intellectual disabilities is crucial not only to inform and educate the child and their parents or legal guardians about the requirements and demands that the disorder may have, but also in order to give them access to whatever supportive measures the school and society at large can provide.

If the assessment is inconclusive, the individual is followed up with psychological evaluations and renewed medical examination after about a year.

Moreover, it is important for the parents to know that they are going to have to request the legal guardianship of their son or daughter when they get to the adult ages, usually 18, in order to be able to have control of their medical, economical and housing duties.

8.4 INTERVENTION, SUPPORT AND FOLLOW-UP

Once the examination process is complete, and the MILD intellectual disability has been diagnosed, the patient is qualified and authorized to get support from habilitation services. Follow-up information about the diagnosis is crucial in this context, because it can help the individual and the family to understand the difficulties that they are going to be facing and to understand the support that they are going to need.

Individuals diagnosed with intellectual disabilities are also authorized to get support through The Swedish Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS). This includes access to a contact person, short stays away from home and short periods of supervision for schoolchildren over 12 years old. Adults with intellectual disabilities can get assistance in daily activities and they can also be offered a residence with special services, usually a house where there are about five people with intellectual disabilities and they have staff that helps them to get through the daily life at the house, or there is also other specially adapted housing where they can live.

It is also obligated for the school to take appropriate measures by providing the person diagnosed with intellectual disability, support and tailored efforts. Individuals with intellectual disabilities are entitled to tailored curriculum, which is a special school curriculum, and in some cases, the special school curriculum can be implemented in regular school environment, but this curriculum is usually only taught in special schools. If the individual goes to a public school, they usually have a staff member that goes with them the hole school day and helps them to realize the activities that the teacher says the students have to do, this can be a problem sometimes when the person with intellectual disabilities does not have the ability to read like the other people in the class, and that means that she or he is not going to be able to do the activity if there is not a lot of help provided.

If a child is diagnosed with mild intellectual disability, it is very important to monitor their development and perform follow-up examinations as necessary to see if there are any changes.

8.4.1 Swedish Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS).

The LSS is an entitlement law that authorizes and requires supplementary support for people with significant and long-term functional disabilities. This law applies to people with intellectual disabilities, people with significant and permanent intellectual functioning disabilities following brain damage as an adult, and people who, as a result of other serious and permanent functional disabilities which are clearly not the result of normal ageing, have considerable difficulties in everyday life and great need of support or service. Any person included in these three statements can apply for assistance. But there are also ten forms of assistance in accordance with the Clause 9 of LSS, and as the LSS - the Law regulating Support and Services to Persons with Certain Functional Disabilities - in brief says, the ten forms are:

1. ***Advice and other personal support*** *to ensure people with functional disabilities and their relatives access to professional, coordinated and permanent assistance from several areas of competence. The expert support shall aim to produce good living conditions and to prevent and reduce the effects of the functional disability. The assistance shall be of an advisory and generally supportive character. Medical, psychological, social and educational aspects of the functional disability shall be taken into account.*
2. ***Personal assistance*** *for people who have considerable need of personally designed care in everyday life. The need may relate to*

help with dressing, managing hygiene, eating or communication with others.

3. ***Companion service*** *for people who need help to get out to leisure or cultural activities, or to participate in social life otherwise.*
4. ***Contact person,*** *that is going to be someone who gives personal support and functions as a friend.*
5. ***Relief service****, which means that a person comes to the family home in order to take care of the person with functional disabilities.*
6. ***Short-term stays away from home*** *to provide people with functional disabilities with recreation and a change of scene, and to give relief to relations. The assistance can be in form of a short-term home, with a family or at a camp or similar.*
7. ***Short-term care for school children over 12,*** *someone who takes care of children over 12 years old with functional disabilities before and after the school day and during school holidays. The operation can be integrated with after-school clubs, be done in special groups or based on personal needs.*
8. ***Living in family homes or housing with special services for children and young people****. As a complement to, or to replace the family home, children and young people can live with another family or in housing with special services*
9. ***Housing with special services for adults or other specially adapted housing for adults****. These can be specially adapted housing, service housing or group housing.*
10. ***Daily activities****, for people with intellectual disabilities, autism or functional disabilities following brain damage as an adult, Groups 1 and 2 as above. The operation can be carried out at a day center or at another place of work.*

There are also other clauses of the LSS such as Clause 8, which talks about the entitlement to submit information verbally, and says that when decision and assistance is to be made in accordance with Clause 9 of LSS, the person to whom the issue relates or the representative of this person will be required to submit information verbally at a meeting with the beard which is to make decisions on the matter, and then he or she must be notified of this entitlement.

Another clause is Clause 10 which talks about the Individual Plan and says that any person guaranteed assistance in accordance with LSS must be offered an individual plan in which assistance decided on a planned is accounted for. This plan will be compiled in consultation with him or her. Anyone who has been granted assistance shall be able to request compilation if a plan at any time, if this has not already taken place, and this plan has to be reviewed on a continuous basis at least once a year.

Another important clause is Clause 27 which talks about appeals, and says that if the person is not satisfied with an LSS decision, they can appeal against it to the Administrative Court, and if their application is turned down, they will also receive information on how to appeal.

8.4.2 Mild intellectual disability in the classroom:

Typically, students with MILD intellectual disability, function about 2-4 years below grade level, even though in some cases the students have the level of kindergarten child when it comes to writing or reading and that's why they tend to express their emotions or feeling by drawing. This deficit tends to affect the child not only academically but also in their speech development, memory and attention span. Students with MILD intellectual disability, often need their lessons to be modified and, depending on the severity of the disability, they may need to receive instruction in a special education classroom. Students with this disability also manifest delays in social development, when suffering of this condition, they may be unable to perceive non-verbal cues in social situations and this could be seen as emotionally immature by their peers, that could make the child suffering from the MILD intellectual disability feel inferior or that they are not enough, that is why teachers have to try to get the other kids to understand what is the situation and teach them how to live with it in their classroom, this feeling of being inferior could often be exhibit with an obsessive-compulsive behavior, and they may need frequent reminders about appropriate social conduct. These students also struggle to distinguish not only concrete and abstract concepts, but also figurative language, such as metaphors, similes, idiomatic expressions and others, which are quite confusing for them.

The most powerful action that teachers can do for students with MILD intellectual disability is to create a positive, encouraging atmosphere which promotes self-esteem, because these students usually struggle with feelings of confidence and self-worth. What happens when you notice and complement positive progress, even though the progress is small or seemingly insignificant, is that the student's self-esteem is reinforced to some degree, and more positive change becomes possible in the future.

These students have difficulties in learning and their learning period is slower when they have to learn new concepts and skills, so it is important to remember that the communication is really important and one's ideas have to be communicated in the simplest and clearest possible way. Sometimes, it is necessary to speak slowly for them, repeat yourself, and ask the student if he or she understands what you are explaining, but always being careful not to "talk down"[18] to the student, because this can cause feelings of inferiority and issues with self-esteem, so when talking to a child with MILD intellectual disability, the best is to keep conversations as normal as possible, always attempting to be as inclusive as you can.

It is really important to establish rules for the classroom, since the student has to know how to follow rules, but these rules should be as simple and clear as possible, due to the fact that students with MILD intellectual disabilities often have trouble following rules and routines, and that is why it is really important to make expectations in class as easy to understand and as predictable as possible. When they do something that is not correct, do not call the student out in front of the whole class, because that is going to have a huge impact on him or her, call her or him afterwards and have an one-on-one discussion, because that is going to work much better.

It is also salient to create a written agreement between the teacher and the student, as the student with MILD intellectual disability may show

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[18] Talk down means to speak about something or someone in a negative way.

maladaptive, unstable or troublesome behavior in the classroom. In this written agreement different aspects should be identified the behavioral goal, the criteria for success, and consequences and rewards for behavior. This must only be addressed to one behavior at a time because, on the contrary, it could overwhelm you and your student.

Students with MILD intellectual disability will need the teachers' help to learn some of the basic life skills, such as organization skills and social skills. Visual cards can help the student a lot and are highly effective for organization. Other activities that can make it easier for the student are visual schedules of the day's activities, either on a bulletin board or on a small card which the student carries throughout the day. They could use both, which can be helpful for learning how to plan the week. Positive social interactions encouraged by the teacher when possible are a good way to make them see what is good and what is bad, but it is also really important to offer guidance away from negative interactions.

Students that suffer from MILD intellectual disability may need shorter periods of work time with a desirable activity or item that will help the teacher to keep the students motivated, because students with MILD intellectual disabilities tend to be highly distractible and they get bored pretty fast.

It is really important for the teacher to be really patient and not get frustrated easily. The environment that the teacher creates in the classroom, the skills that the teacher teaches, and the encouragement that the teacher gives to the students may be the key to a successful future for these students, because children with MILD intellectual disability could in fact learn to live independently as adults.

8.5 TEENAGER'S YEARS WITH MILD INTELLECTUAL DISABILITY

Teenage years are always difficult years, full of insecurities and self-esteem problems. Teenagers with intellectual disabilities face many challenges that are common to their typically developing peers, however, the way they cope and resolve these challenges is different. The struggles related to their disabilities that make it more difficult or sometimes even impossible for them to face these challenges, and to participate in social activities at the same level as their peers, can result in a negative psychosocial outcome such as stress or a loneliness feeling. Adolescents with intellectual disabilities, in general, have more support needs than their peers without intellectual disabilities. Giving support to adolescents with intellectual disabilities is often complex and depending on who provides the support and how they provide it, it is going to affect and help the teenager suffering from MILD intellectual disability in one way or another.

It has been studied by many scientists and doctors in different occasions. that providing support to teenagers with intellectual disabilities increases opportunities for adolescents with intellectual disabilities to maintain and create friendships and express themselves better and gain problem-solving skills. It has also been proved that if the support that these teenagers receive is from someone that is not part of their family, there is a better outcome due to the lack of confidence that the adolescent has when he or she has to deal with some situation that the staff has created for him or her to face. When this happens, the teenager that suffers from the intellectual disability tries harder to face it than if the staff member is someone that he or she knows more deeply.

The areas that are explored in the life of a teenager that suffers from an intellectual disability are the ones that most directly impact the development in adolescents, like friends, family, peers, school, extracurricular activities, technology and the Internet, bullying and psychosocial development. These areas are chosen because of their importance in the lives of adolescents with disabilities, and the potential influence that these can have in the process of preparation and transition to adulthood. These areas are also chosen because they are the most widely studied areas in typically developing adolescents and this helps to compare the differences. Even though these areas are the most common studied ones, there are other areas like

Picture 13: Quincy and her cousins

sexuality and social interaction that also have a big impact on the life of teenagers with intellectual disabilities.

8.5.1 The Internet and teenagers with intellectual disabilities

Nowadays, the Internet is surely an important part of the life of teenagers and that makes it even harder for MILD intellectual disabled adolescents to feel like normal teenagers. They also want to have social media and they do not have the same maturity levels as the other teens of their age. For teenagers with MILD intellectual disability, something could be very funny and they think it is a good option to post it online, but this can cause the other teenagers to make fun of them, or just laugh at it. Even though they are probably not laughing at it with a bad intention, it could affect the feeling of the MILD intellectually disabled teenager a lot. If she or he sees someone laughing, she or he may think that they are making fun of her or him even if what the others are laughing at has nothing to do with them. This is why the parents, legal guardians and staff from the teenagers that suffer from MILD intellectual disability have to be extremally careful when it comes to what the teenager posts or does with her or his social media. However, the use of the Internet can help these teenagers to learn in a more effective way, they can use some apps such as *“MentalUP”* or *“Otsimo”* that help them learn how to read or how some words are written in an easier way than if they have to learn them using a paper and a pen. They perceive that learning as a game and they do not get tired of it and do not get bored.

Picture 14: Quincy working on her iPad

Even though there is this negative part, there are also positive parts of the use of the Internet and technology by adolescents with intellectual disabilities. Technology can help these individuals to improve their quality of life, establish independence, and strengthen their identity. Furthermore, technology can be used to teach teenagers with intellectual disabilities daily living skills in an easier way and it can serve as a method to remind them to complete necessary daily activities, such as brushing their teeth, eating, cleaning or bathing.

8.5.2 Friendship relationships

The creation of friendship and its development of those can be difficult for teenagers with disabilities, especially as they try to understand their disability and how they get along with others.

The friendship of teenagers with intellectual disabilities is characterized by less warmth or closeness and less positive reciprocity than the friendship of their peers. By the same token, teenagers with disabilities spend less time with friends outside school and are less likely to have a cohesive group of friends, this is due to their maturational level, because they cannot be alone with another friend without an adult taking a look on them. Youngsters with intellectual disabilities are usually seen as less socially competent and of lower social status, which makes them struggle when it is time to resolve social conflict with peers.

Even with these difficulties in the development of friendship, most adolescents with disabilities have more satisfying friendship with peers who also suffer from an intellectual disability, and tend to be more stable and positive than friendship with typical developing peers

8.5.3 Sports and extracurricular activities

Sports are the most common extracurricular activities for teenagers with disabilities. The participation in these activities makes them feel like the other teenagers and makes them feel good. It also provides athletes with an opportunity to interact with other people and bound friendship that provide them with a variety of important self-enhancing benefits. Most of the individuals who participate in sports are committed to and enjoy their sports experience and they often use sports as a means to improve their quality of life and form of identity.


Picture 15: Quincy and her best friend Max, who suffers Autism

In the United States of America, there is an organization, which has been expanded world-wide, with the name of Special Olympics. It is an organization that creates a network of sports competitions and activities for people with disabilities. These activities are just for people suffering from disabilities and not for typically developed kids, this is because individuals with disabilities are often slower on the sport or they have some difficulties when practicing it. Taking part in activities such as swimming or bowling with other people with special needs helps them to realize that they are not alone and there are others going through similar challenges. It also lets them take a break of their daily life responsibilities and have a good time while practicing sports that they enjoy.

8.6 FUTURE OF A PERSON SUFFERING FROM THIS DISABILITY

For people suffering from an intellectual disability, aging can bring progressive health risks coming from early age-onset[19] conditions. Intellectual disabled older adults are also prone to suffer multi-morbidity[20], and the most common ones are mental illnesses, epilepsy and gastro-esophageal reflux disorder.

There have been some studies that have studied the effects of age and gender on these disabilities and the difference of non-intellectual disabled people and intellectual disabled people when it comes to suffering from two or more physical conditions. As it is seen in graphic 1, it is more common for people suffering intellectual disabilities to suffer physical conditions when they get older, but it is also seen that co-morbidity is highly prevalent at all ages.

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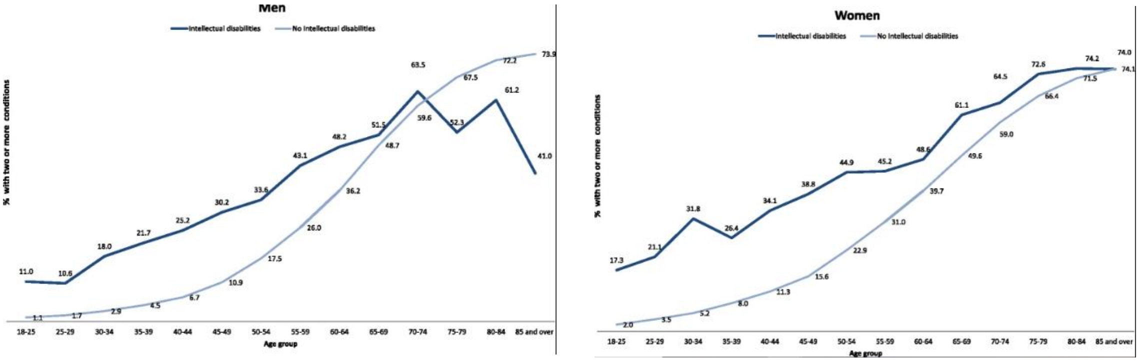
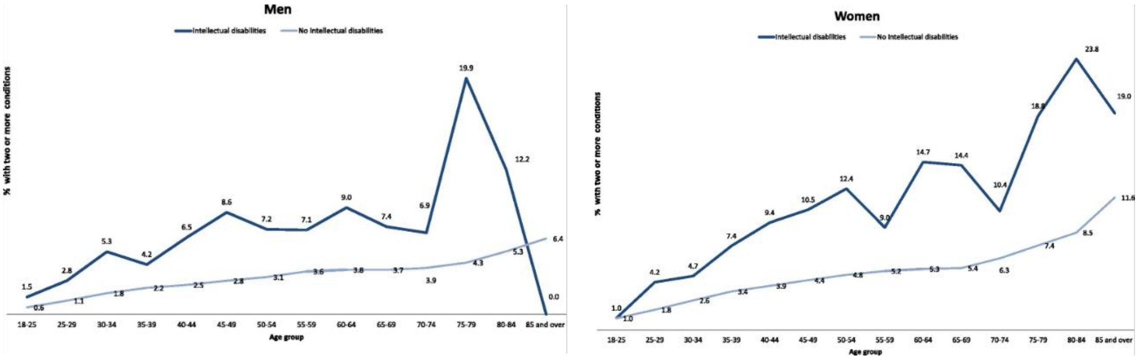
[19] Age-onset meaning the chronological age at which symptoms of a disease or disorder first appear in an individual.

[20] Multi-morbidity is the presence of two or more chronic conditions that a person suffers at the same time.



Picture 16: Graphic 1 – physical conditions comparison

Another study that was made was the proportion of people with two or more mental health conditions, this study was made distinguishing gender and age groups as well. The results, shown in graphic 2, show that the percentage of people with intellectual disabilities, both men and women, who suffer from more than one health condition is higher than non-intellectually disabled people.



Picture 17: Graphic 2 – Mental Health Conditions comparison

However, most adults that suffer from a MILD intellectual disability can succeed on their own and live a typical life, even though they might need a minimal support. Even though they are expected to be able to live a typical normal life, their daily life is extremally hard because they face lots of discriminations and exclusions. This can also bring up other disorders like mental health problems such as anxiety and depression.

8.7 PARENTS AND FAMILY

Family relationships play an extremally important part in the development role of teenagers with intellectual disabilities, we should take into account the fact that teenagers with intellectual disabilities rely heavily on their families when it is time for them to form an identity and explore relationships outside the family. Every single family member plays a role, but parental and sibling relationships are really important and are the ones that impact the most in the life of the adolescent with disabilities.

Picture 18: Quincy with her sister and her step-grandmother

Even though every member of the family takes over new challenges during their daily life when the intellectually disabled teenager goes through the transitioning phase from childhood to adolescence, mothers are the ones that are especially vulnerable to unique types of parenting stress, and that is because they often fill the role of primary caregivers, even though this can affect all the members of the family, family members can also suffer from mental health problems, which can be related to factors such as feeling social isolation and sometimes they could experience feelings like disappointment, embarrassment, or feel guilty as they recognize that their child may never reach the goals they had envisioned for them.

Picture 19: Quincy and Christy, her mom

While the teenager learns and develops an independent sense of self, parents also have to learn and explore the best way in which they can help their children with the transition. Parents have to learn ways to teach the adolescent with disabilities about potential limitations of their disability, ways to grant and limit freedom to their child and ways to redefine their roles as parents. Communicating with their child about their disability, including differences and limitations, helps parents and families to successfully navigate the adolescent period.


Picture 20: Quincy, her mom, her dad, her biological sister and her Catalan sister

Doctors recommend parents to get support and assistance to reduce stress during the early childhood years, due to the fact that it can benefit both parents in their future relationship with their adolescent child that suffers from MILD intellectual disability. Furthermore, doctors determine that there is an urgent need for emphasis on early intervention and education programs to help families, parents and children manage and reduce problem behaviors, and increase good parent-adolescent relationships.


Picture 21: Quincy, her biological sister and her Catalan sister

In the period of transition into adolescence sibling's relationships play an important role because social opportunities are less prevalent for youth with disabilities than for typical developing youth. Given the limited social area, siblings relationships can provide an opportunity for teenagers with intellectual disabilities to feel like they are also a part of society and they can have the feeling of warmth and closeness. It also helps them to learn requisite skills and appropriate behaviors, and they learn that through observation and experience.

There are several factors that can play a role in the sibling relationship quality and the closeness that the adolescent with disabilities have with their siblings. The level and quality of this relationship can be affected by the typically developing siblings' understanding of their sibling's disability and its implications. As the individual with disabilities gets older, the siblings, either younger or older, often take on a parent or caretaker role and begin to realize that one day they might have the responsibility to take care of their brother or sister.

Most siblings affirm that they would not change anything about their life, even though they recognize the challenges it presents to the family, they say that the positive experiences they have with their siblings with disabilities outweighs the negative ones. It is also true that sometimes it is really hard for the sibling of the individual with disabilities to live with the fact that their brother or sister acts differently from other people, and that makes the relationship not as good as it could be. Sometimes, the sibling feels ashamed of what the disabled individual does and that can bring up fights between them because the sibling tries to explain to their brother or sister that what they were doing was not appropriate for someone of their age, even though they are not doing anything wrong.

A common concern of parents and siblings of teenagers with disabilities is that they have fewer friends, less opportunities for friendships, and lower participation rates in social and recreational activities. This could possibly result in greater loneliness throughout their teenage years.

8.7.1 Christy Kopp's interview

In order to understand how the life of parents with an intellectual disabled son or daughter is, Christy Kopp was interviewed. Christy Kopp is the mother of Quincy Kopp, an 18-year-old girl with Mental Retardation – high functioning clinical diagnosis. Christy is a 45-year-old woman with American Citizenship who lives in the state of Indiana with her husband, Jason Kopp, her older daughter Quincy Kopp and her younger daughter Jalyn Kopp. She has worked in the medical field, on Dialysis for more than 20 years, and in 2020 she decided to start working as a staff member for people with intellectual disabilities with the main objective of providing the care that intellectual disabled people deserve.

In this interview, she explained that when Quincy was around two years old, she had an episode while eating in her highchair where she could not move, blink, cry and her body was stiff. At this moment they realized that something was not working properly and took her to the doctor. Later on, the doctors told them that the episode that they had lived was a silent seizure and from then on, they started to do tests to see what was happening to Quincy.

She also tells that Quincy graduated from high school, with a basic diploma, since she is around 8-9 years mentally behind her peers and could not do most of the activities they had to do in class. Last June, she joined the company Life Choice, which is a company that works with people with disabilities, and where Mrs. Christy Kopp also works. She explains that Quincy has a PAC, who is a personal assistant for care, staff worker who works with Quincy 3 days a week for 4 hours and takes her around, out into the community for activities such as shopping, lunch or going to the park. Quincy works on daily living skills every day, with both family and staff, Mrs. Kopp said that, at home, they work a lot on independent activities, she also told that Quincy is on a very scheduled routine until mid-morning that includes getting herself up, have a shower, getting dressed and brushing her teeth and her hair for the day, then she fixes herself breakfast with some assistance and after that, they work on chores such as putting away dishes, taking out the trash, running the vacuum and other household activities.


Picture 22: Quincy graduating from high school

Quincy is not working at the moment but she volunteers at a farm that has many different animals. As Mrs. Kopp says, Quincy is a lover of animals and loves spending time with them. The Kopp’s family have a special trained dog named Dozer that works as an


Picture 23: Quincy and her dog Dozer

emotional supporter for Quincy.

Mrs. Kopp did also talk about public schools when it comes to special needs for children, she said that in the United States of America, Public School and Special Education is not a good combination. As she says, most public schools are really far behind for what each special need. They are usually all together in one classroom at a 4-1 ration, 1 teacher for the whole class and 1 teacher's aide for every 4 students with special needs, they mix them with typical developed students who obviously have a higher academic level, the difference of the learning levels of the students makes it very hard to teach and that ends up with the special needs' students receiving the bare minimum for education.

Picture 24: Quincy at swim practice

As she explained, Quincy participates in Special Olympics where she swims and bowls, but she has also participated in basketball and volleyball. Quincy is a very successful swimmer and she has won many medals. Mrs. Kopp mentioned that Quincy is a totally different person if she does not have swimming practice, as practice helps her to take a break from real life and be happy without worrying.

Mrs. Kopp said they try to let Quincy be as independent as possible, but she needs assistance in lots of activities since she only reads at a preschool level and requires assistance when cooking, or going out into the community. Quincy receives staff services 54 hours a month, and that is about 12 hours a week. Mrs. Kopp says that other than those 54 hours a month, herself and her husband work with Quincy every day to become the best version of herself she can be.

Christy also said that being a mom of an intellectual disabled person is the hardest thing in the world because her daughter looks like a normal beautiful 18-year-old girl but has the mind of a child, and, as she assured, it is hard to watch others judge your child because she does not have a "*sing flashing*" - "I am mentally handicapped"-. She explained that they, wake up every day as a new day, but the worst part is that, as Mrs. Kopp says, you are her safe place so on bad days mom, dad, and sister get the worst of the behaviors because they are where Quincy feels in her safe zone to act out.

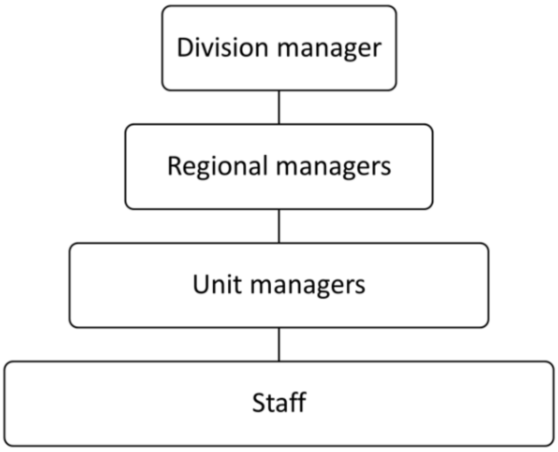
As a conclusion of the interview, Christy said that there are not enough things, people or places for individuals with disabilities, she also says that intellectual disabled people will struggle their entire life for staff, services, government assistance because there is never enough hours or money. She also expressed that there are so many people left alone to fend for themselves. As a result, there is a mass of mental health crisis amount the people suffering from intellectual disabilities and their families.

She affirmed that she could go on about mental health and the needs of these individuals forever, she expresses that so many people are unaware of the Special Needs community and all the aspects it covers.

8.8 STAFF SERVICES

Staff services are one of the essentials in the life of a person with an intellectual disability, due to the fact that these people help them in a lot of ways and are the ones that teach them most of what they know and what they need for their basic life.

There are different levels in order to organize the organizations that work with special needs people, every person with special needs has a staff member, but if something goes wrong with that staff member, they have an upper-level person to contact and find solutions. These levels are from the lowest to the



Picture 25: Staff positions and levels

highest position. Staff, Unit managers, Regional managers and Division managers. The one that is in touch and actually work with the special needs person is the staff member, but there is a hole team behind.

Being the staff member of an intellectual disabled teenager is not the easiest job, they deal with lots of situations and challenges and they have to be able to know how to manage those situations. Sometimes, it is difficult to make an intellectual disabled teenager understand that what they are doing is not appropriate as they feel that you are accusing them. As a result, the staff members of adolescents with intellectual disabilities have to be very patient and nice in order to have a good relationship with the teenager.

8.8.1 Rena's Witham interview

In order to find out more information about what the job of the staff members is, and since there is not a lot of information online or in books about these services provided to the intellectually disabled people, and interview was made to Rena Witham, Quincy's old staff member. Rena is a 20-year-old woman with American Citizenship who lives in the state of Indiana with her two mothers. She graduated high school in 2020 and she went to collage for a semester at Kentucky before becoming Quincy's staff member.

Rena first explained why she worked as the staff member for Quincy. She said that the decision to work as a staff worker was offered to her as an opportunity, she had just gotten home from college and she wanted to experience options for what she thought would be her future career path. She said she felt as though this was a great opportunity to branch out and try something new that interested her, she had never worked with special needs before but she had always loved and supported the people who work their hardest for these amazing people. She affirmed that this was an amazing opportunity that would allow her to branch further into the idea and break an introduction into her future career path options. She explained that in order to become a staff for a special needs person, she had to interview with her supervisor, who had to ask her several questions, after they decided that Miss. Witham was qualified for the job, Rena had to go through a lot of videos and answer questions. Those videos were very informative and allowed her to know how she should handle situations and what to face different situations. Those videos also informed her on vocabulary and terms she did not know before. Miss. Witham stated she also needed to go through a background check in order to get the job.

When she talked about her job, she said that her work with Quincy, was educational. They worked on everyday matters such as sweeping, washing dishes, doing laundry, and other household chores. She says they also worked on public safety, and as she specified, they would work on looking both ways before crossing the road, being cautious in the parking lot, and stopping at stop signs. She affirmed that they spent a lot of time working on reading, reading small simple books, looking at signs and pictures and talking about them. They also worked on coloring and many art projects, because as Miss. Witham says, Quincy loves art. She said she used to focus a lot on teaching her how to use money and build money skills by going shopping.

Their daily routine was very similar every day, as Rena said. Miss. Witham would go to get Quincy every morning around 8 am. They would both go to Rena’s house and she ask Quincy what she preferred to do. As Rena says, most days Quincy did not care about what they did or worked on, they read every day before she would take her home. Miss. Witham affirms that sometimes Quincy would be defiant and not want to do what she was being asked, so they would change ideas or take a break and go back to the activity later.

According to Rena, it was not a difficult job. She said it was an easy job if you listened and allowed yourself to get close and get to know your patient. She assures she enjoyed that job very much. As Miss. Witham explained, the period of time in which she worked with Quincy was a learning period, she learned something new each and every day, and that is one of the reasons she says that her job was an adventure but in the best ways. As she said, the feeling of getting to know someone and trying to understand someone that you may not have understood before is a beautiful aim, and as she assured, she enjoyed her job very much.

She pronounced that her experience were lessons learned, memories made, and many other things, she said she really enjoyed working with Quincy. She also helped other staff with their patients. She also expressed how good it felt to work from home in comfort, allowing her patient to be comfortable and feel as if they were home, she wanted this to be the best experience for them every day. Her experience will always be with her because it put her on the path where she is now.

According to Christy Kopp, she says that there is not enough help for special needs at all. There could be more places for them to work, hang out and be comfortable. There also needs to be more involvement from schools for special needs. She feels like there are not nearly as many opportunities as there are for everyone else. Moreover she says that she feels like they should have equal opportunities.

9. ORGANIZATIONS THAT WORK WITH PEOPLE SUFFERING FROM INTELLECTUAL DISABILITIES

There are multiple types of organizations that work with intellectual disabled people: staff helping them to learn how to carry out basic skills, organizing sports events where they can compete and feel like the typical developed people.

Special Olympics is an organization that has been mentioned earlier by Christy Kopp, and it is one of the most important and known organizations in the world. But there are also other organizations and companies that work for these people and help them to be successful in daily basis.

9.1 SPECIAL OLYMPICS

Special Olympics is a global organization, which was started by Eunice Kennedy Shriver, sister of former President of The United States of America

Picture 26: Special Olympics Logo

John F Kennedy. It changes the life of special need people by promoting understanding, acceptance and inclusion among people with and without intellectual disabilities. Their main goal is to create a better world by fostering the acceptance and inclusion of all people, and through the power of sports, help people with intellectual disabilities to discover new strengths and abilities, skills and success.

This foundation provides individuals with intellectual disabilities, who are eight years old or older, with year-round sports training and athletic competitions, where they involve more than 20 Olympic-type summer and winter sports.

Special Olympics supports over 5 million athletes, 1 million coaches and volunteers, more than 100.000 competitions each year, and 32 Olympic-type sprot through programs in more than 170 countries.

Picture 27: Special Olympics Winter Games 2017

This organization is now celebrating more than 50 years since its foundation. It was inaugurated in 1968 but it was not until February 15th, 1988 that the foundation Special Olympics was officially recognized by the International Olympic Committee. It all started in June 1962 with support from the Joseph P. Kennedy, Jr. Foundation, when a summer day camp for mentally challenged children was organized at Eunice Kennedy Shriver's home, in Maryland. From then on, the Kennedy foundation promoted the creation of dozens of similar camps in the United States of America and Canada, and special awards were developed for physical achievements. It was on July 19th and 20th, 1968, when Shriver persuaded the Chicago Park District to join with the Kennedy foundation in sponsoring a "Special Olympics" held at Soldier Field. About 1.000 athletes from 26 states and Canada participated. Those games where a total success and it was in December that the Special Olympics, Inc., now known as Special Olympics International, was founded.

There were chapters in the United States, Canada and France, and the first Special Olympics World Winter Games were celebrated from February 5th to February 11th 1977 in Colorado. It was by the early 21st century that the corporation expanded a lot and there were nearly 200 countries involved. There are annually 20.000 meets and tournaments held worldwide every two years, alternating between winter and summer sports that last for nine days and in which more than one million athletes participate.

Picture 28: [Special Olympic Summer Games 2010]

The Special Olympics athletes find joy, confidence and fulfillment while playing on the field and in life. This organization has found the power to transform lives in sports, where the athletes suffering from intellectual disabilities discover that they can do whatever they want, they are going to achieve their goals as other typically developed people.

9.2 LIFE CHOICE

Life Choice is a company that provides care services to individuals that suffer from intellectual disabilities. It is all around the United States of America but its main office is in New Palestine, Indiana. This company works cooperatively with each individual, their family, support team and country or state entities to ensure quality services. Specific services and support that are offered to the individual are set on by his or her personal strengths, preferences, interests, desires and goals.

Picture 29: [Life Choice logo]

The services that Life Choice provides are supported living services. These services include residential habilitation services, community habilitations services, participant assistance and care, behavior management services and respite services.

Picture 31: Program from an activity for Halloween

Picture 30: Program from an activity for Halloween

This company does not just provide services, they also create fun activities for all their clients in order for them to have fun. Some of the activities that they host are Trunk or Treat during Hallowing, where they encourage their clients to go there wearing costumes and having fun. This is one way in which all the individuals that suffer from intellectual disabilities can have fun and enjoy Halloween without feeling out of place. During Halloween they also organize a monster mask party for the disability community.

During Christmas time they also host a party for all of their clients to celebrate Christmas together and have an amazing time. In these parties they play games, eat deserts that the individuals have made and have a wonderful time together.

Life Choice tries to give as much visibility as possible to the disability community, they take part in festivals as Riley Festival[21] celebrated in Greenfield, Indiana, doing

Picture 32: Life Choice walk at Riley Festival

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[21] Riley Festival is one of the largest craft festivals in the state of Indiana, with designated areas for food, commercial, and flea market booths. It begins every year on the first Thursday of October in downtown Greenfield, Indiana.

a walk, in order to give more visibility to the community. In that festival, their slogan is “LIFE CHOICE ROCKS”.

PRACTICAL PART

All the pictures and graphics used in the practical part are self-made.

10. COMPARISON BETWEEN THE KNOWLEDGE OF INTELLECTUAL DISABILITIES IN CATALONIA AND IN THE UNITED STATES

My main objective was to end up studying the differences between the knowledge that people have about intellectual disabilities in Catalonia and in the United States of America.

In order to compare the knowledge of the people from both places, I created a questionnaire which I sent to both Catalan and American people that has allowed me to come up with some results. This questionnaire was anonymous, in order to keep the privacy of the participants.

The Catalan questionnaire was answered by 183 people, and the American questionnaire was answered by 61 people.

The questionnaire consists of nine quick and easy questions. These questions are the following and are the same questions for both Catalan and American people:

1. Age
2. Gender
3. Have you ever heard about intellectual disabilities and do you know what they are?
4. Which ones of the following are intellectual disabilities?
5. Do you know anyone that suffers from an intellectual disability?
6. If you said YES in the previous question, which intellectual disability do they suffer?
7. Do you know any organization that provides extracurricular activities for people with intellectual disabilities?

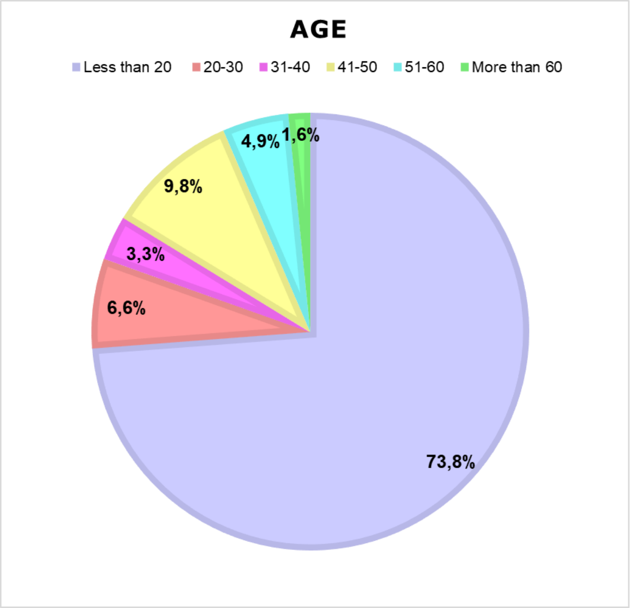
8. If you said YES in the previous question, which ones do you know?
9. Do you think there is enough knowledge and visibility about intellectual disabilities?

The first question, as seen above, is asking the age of the person who was answering the questionnaire, I decided to ask the age in order to get a little more detailed information of the people that answered the questionnaire.

I divided the ages in six groups. It starts with people younger than 20, then the group of people between 20 and 30 years old, followed by the group of people that are 31 to 40 years old, after that the group of people that are between 41 and 50 years old. Next the group of people that are 51 to 60 years old and finally people older than 60.

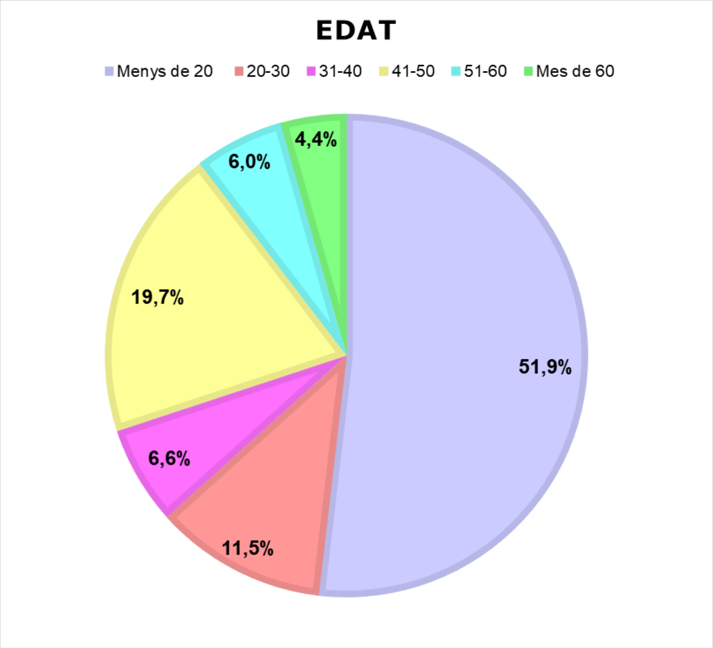
In the American questionnaire, it can be seen that there was a lot of participation from younger people rather than older people.

The 78.,8% of the answers, which is a total of 45 people, were younger than 20 years old. The 6,6% of the answers, which is a total of 4 people, were 20 to 30 years old. The 3,3% of the answers, which is a total of 2 people, were 31 to 40 years old. The 9,8% of the answers, which is a total of 6 people were 41 to 50 years old. And the 1,6% of the people, which is just 1 person, was older than 60 years old.



Graphic 1: Question 1 American questionnaire

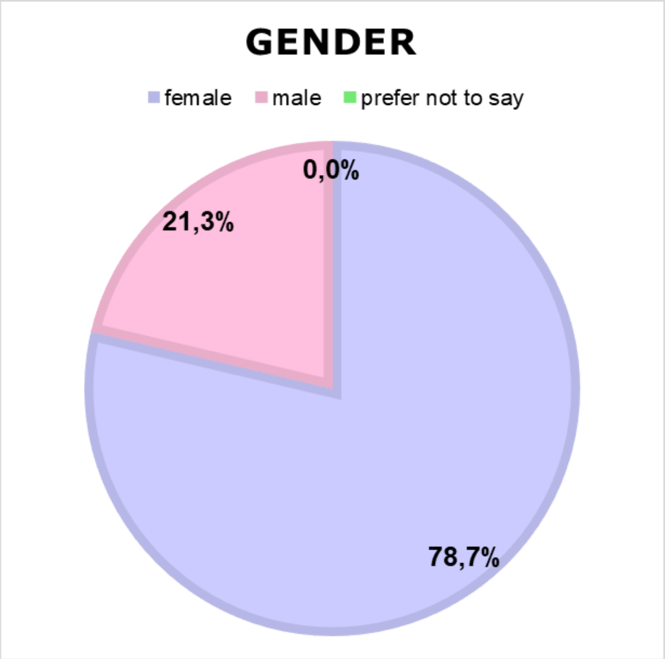
In the Catalan questionnaire, there also was more participation from younger people rather than older people, but as seen in the two graphics, there was a bigger range of age in the Catalan questionnaire. The 51,9% of the answers, which is a total of 95 people, were younger than 20 years old. The 11,5% of the answers, which is a total of 21 people, were 20 to 30 years old. The 6,6% of the answers, which is a total of 12 people, were 31 to 40 years old. The 19,7% of the answers, which is a total of 36 people, were 41 to 50 years old. The 6% of the answers, which is a total of 11 people, were 51 to 60 years old. And the 4,4% of the answers, which is a total of 8 people, were older than 60 years old.



Graphic 2: Question 1 Catalan questionnaire

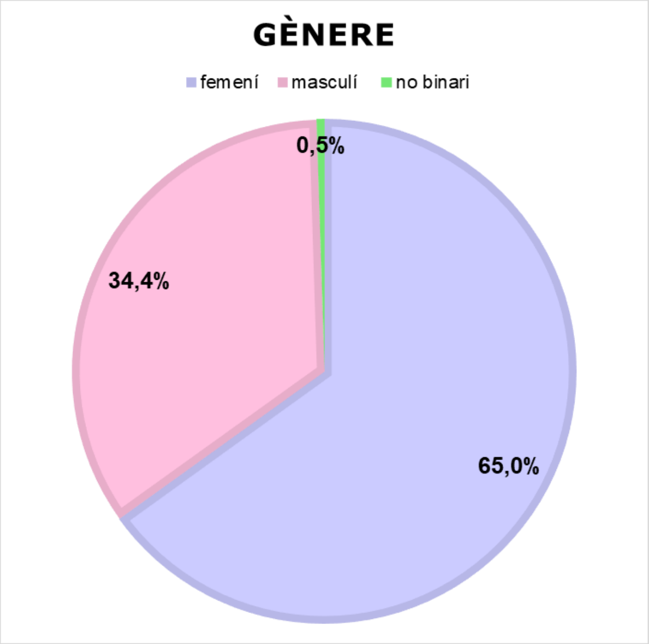
Once asked the ages, I also asked the gender for the same reason, so I could have more detailed information about the population answering the questionnaire.

There were 61 Americans that answered the questionnaire, the 78,7% of the people that answered the questionnaire, which is a total of 48 people, were females, and the 21,3% resting, which is a total of 13 people, were males. There was no one that answered “prefer not to say”.



Graphic 3: Question 2, American questionnaire

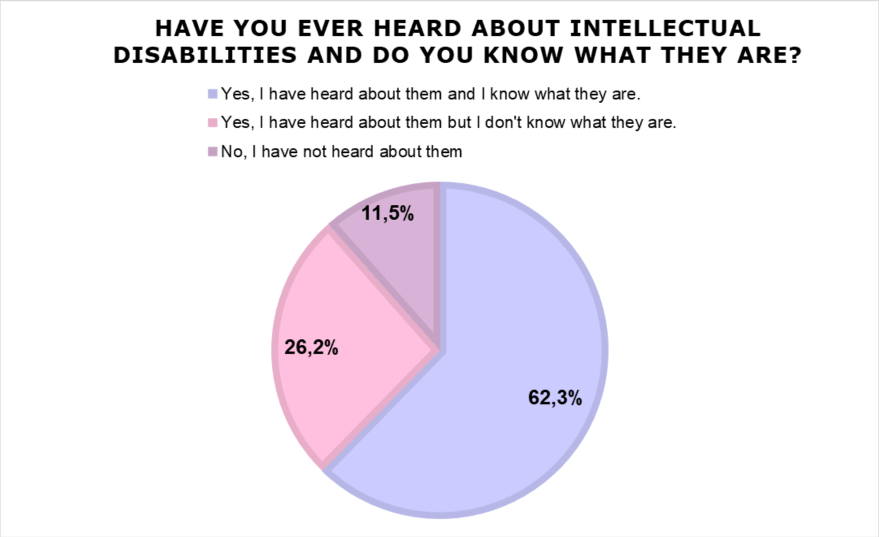
On the other hand, there were 183 people that answered the Catalan questionnaire. The 65% of the Catalans that answered, which is a total of 119 people, were females. The 34,4%, which is a total of 63 people, were males and there was one person, which is the 0,5%, which answered non-binary.



Graphic 4: Question 2, Catalan questionnaire

To begin with the questions that helped me get the answers that I needed to be able to compare the knowledge, I asked if they had ever heard about intellectual disabilities. There were three options to choose as an answer. They could choose between: “Yes, I have heard about them and I know what they are.”, “Yes, I have heard about them but I do not know what they are.” and “No, I have not heard about them”.

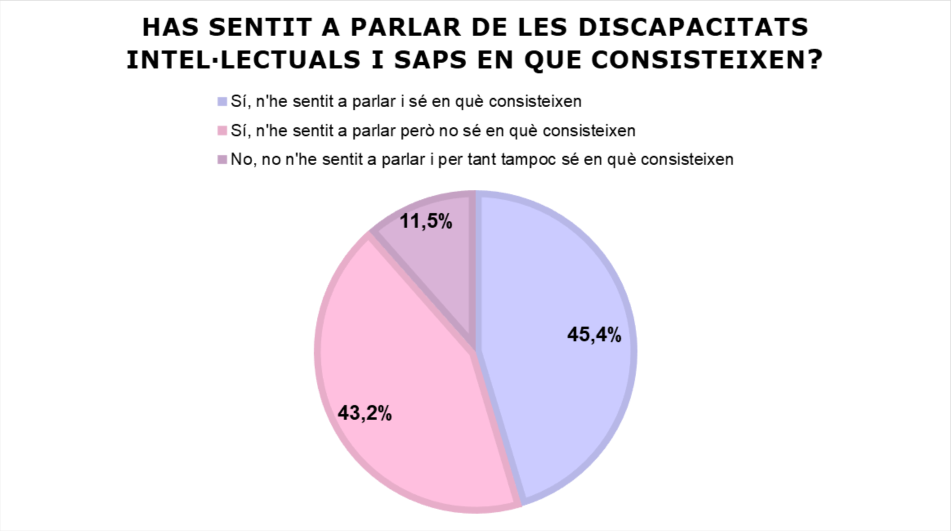
In reference to the American questionnaire, there were 61 answers to this question. The 62,3% of the answers, which is a total of 38 people, voted “Yes, I have heard about them and I know what they are”. The 26,2% of the answers, which is a total of 16 people, said “Yes, I have heard about them but I do not know what they are”. And the 11,5% left, which is a total of 7 people chose the answer “No, I have not heard about them.”



Graphic 5: Question 3, American questionnaire

As a difference, when looking at the graphic of the Catalan questionnaire, it is seen a difference on the numbers of people that have heard and know about intellectual disabilities and the people that do not know about them.

Comparing numbers with the Catalan questionnaire, and knowing that there were 183 answers to it, we can see that the 45,4% of the people, which is a total of 83, chose as an answer “Yes, I have heard about them and I know what they are”. The 43,2% of the answers, which is a total of 79 people, said “Yes I have heard about them but I do not know what they are". And finally, the 11,5% left, which is a total of 21 people, chose as an answer "No, I have not heard about them, and as a result I do not know what they are".



Graphic 6: Question 3, Catalan questionnaire

Once seen the results of both graphics for Question 3, I can say that, even though there were more people that answered the Catalan questionnaire, there is a bigger number of Americans that have heard and know about intellectual disabilities, which gives me a little advancement on who has a better knowledge about these disabilities, even though I still think the amount of people that have not heard about intellectual disabilities and do not know about them is too big.

After asking this question, I decided that I had to ask the people that answered the questionnaire to choose which of the terms listed were terms that referred to intellectual disabilities, because as I had read during the research period, there are a lot of people that confuse intellectual disabilities with mental disorders.

In order to see if this was true, I listed the following terms:

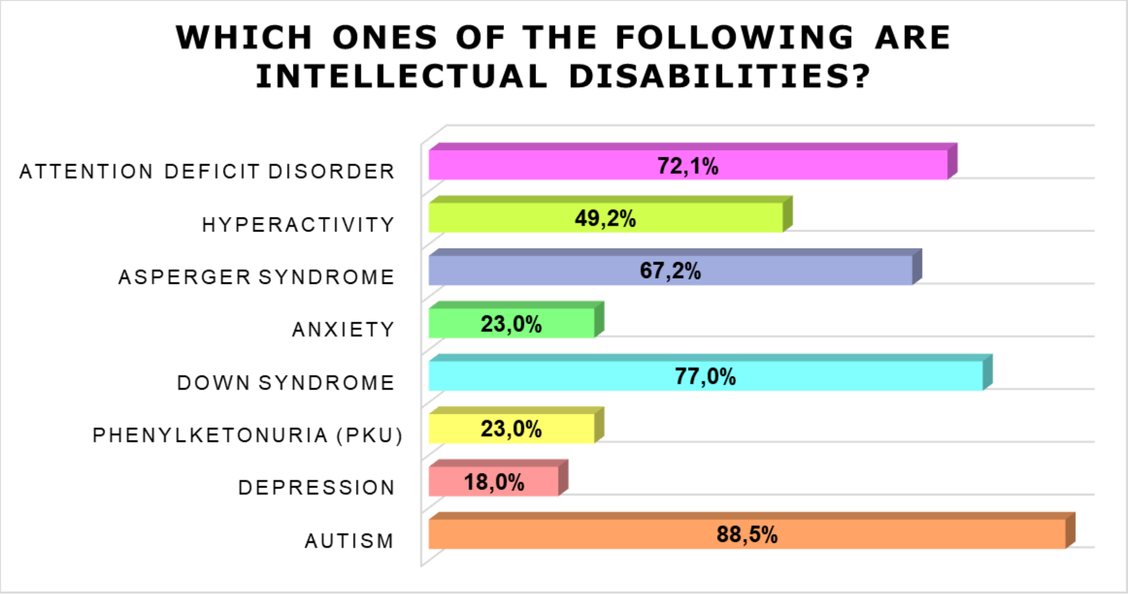
- Autism
- Depression
- Phenylketonuria (PKU)
- Down Syndrome
- Anxiety

- Asperger Syndrome
- Hyperactivity
- Attention deficit disorder

In this question, the people answering had to choose which ones they thought were intellectual disabilities, and they could choose more than one option. The terms that refer to disorders that are considered intellectual disabilities are Autism, PKU, Down Syndrome and Asperger Syndrome. The other terms are not considered intellectual disabilities, but mental disorders, which I had read most of the people confuse as intellectual disabilities.

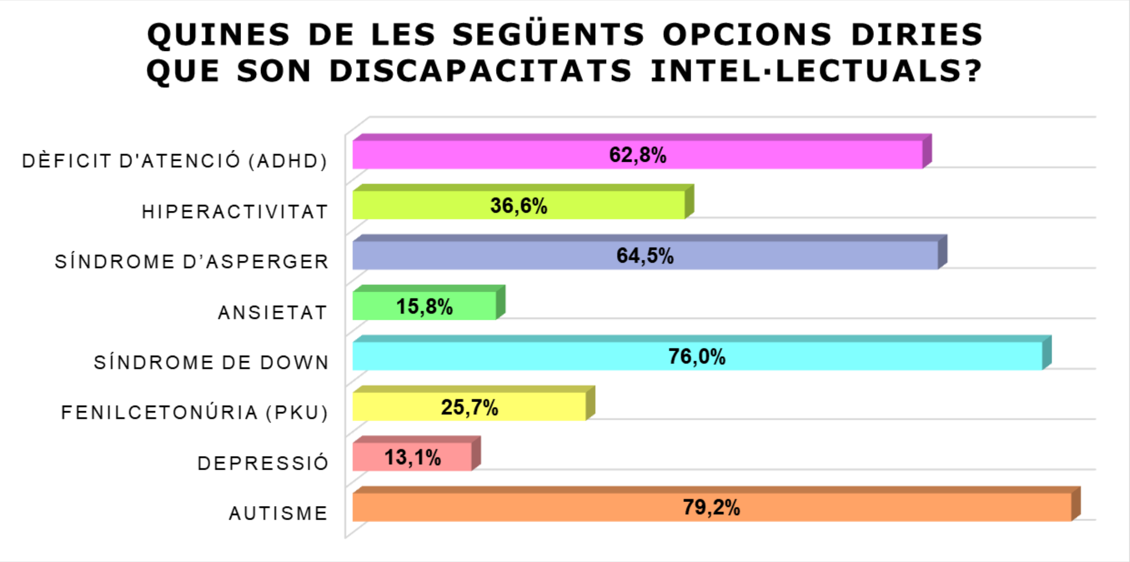
Regarding the American questionnaire, there were 54 people that answered that Autism is an intellectual disability, 11 people said that depression is an intellectual disability, 14 people also chose PKU as an intellectual disability, 47 people said Down Syndrome was an intellectual disability, 14 people chose Anxiety, 41 people said Asperger Syndrome was considered an intellectual disability, 30 people chose Hyperactivity as one, and finally 44 people answered that Attention deficit disorder was one.

As seen by the results, there are a lot of American people that confuse intellectual disabilities with other mental disorders and that shows us there is not enough knowledge about what an intellectual disability is.



Graphic 7: Question 4, American questionnaire

On the other hand, the Catalan people answered pretty similar to the American people, regarding the confusion. 145 people chose as an answer Autism, 24 people confused depression as an intellectual disability, 47 people said that PKU was an intellectual disability, 139 people chose as an answer Down Syndrome, 29 people were wrong and confused Anxiety as an intellectual disability, 118 said that Asperger Syndrome was considered an intellectual disability, 67 people confused Hyperactivity with an intellectual disability, and finally, 115 people also confused Attention deficit disorder as an intellectual disability.



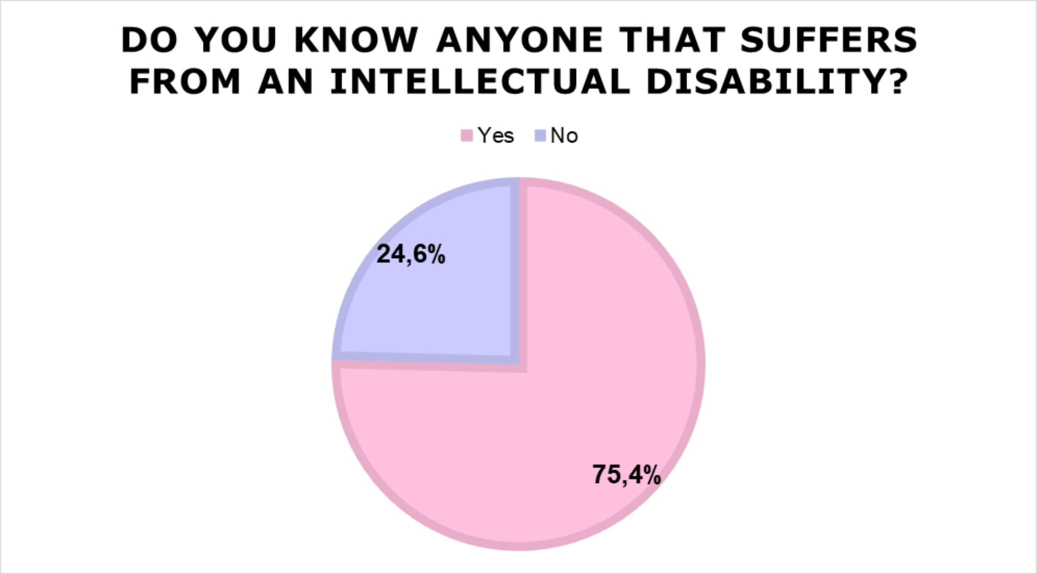
Graphic 8: Question 4, Catalan questionnaire

Once I had these results, I could see that confusing intellectual disabilities with mental disorders has nothing to do with one's culture because in both questionnaires there were lots of people that confused Depression, Anxiety, Hyperactivity and Attention Deficit Disorder as intellectual disabilities. This showed me that in both countries, there is not enough knowledge about intellectual disabilities because the people of both countries confuse intellectual disabilities with other mental disorders that have nothing to do with intellectual disabilities. This let me know that even if there is a little knowledge about these disabilities, there needs to be more in order for the people to be able to differ both intellectual disabilities and mental disorders.

After this question, I also asked if the people answering the questionnaire had any family member or knew a person that suffers from an intellectual disability. In order to respond to this question, they had two choices as an answer, Yes and No.

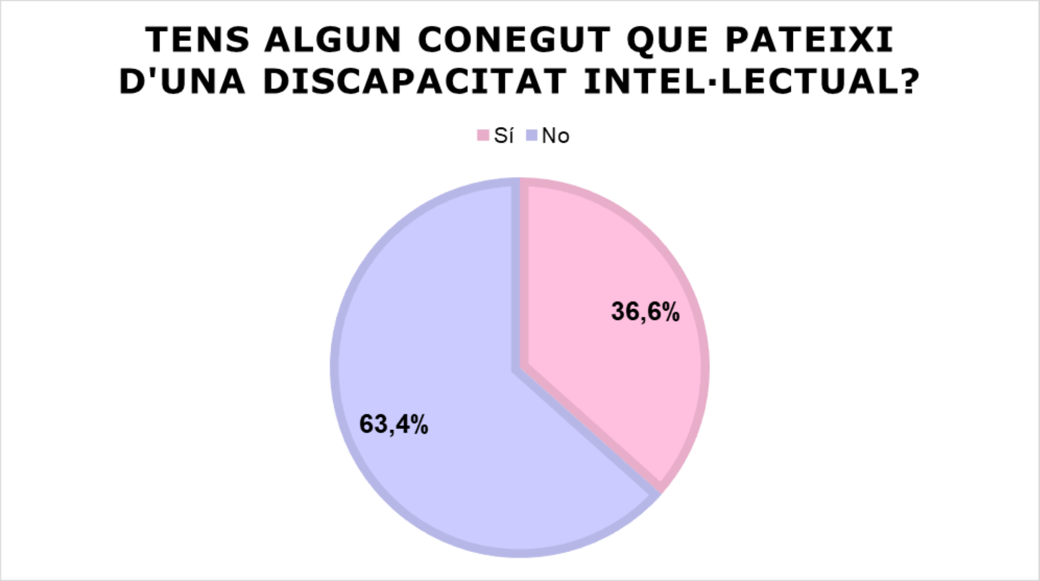
In the American questionnaire there were the 75,4% of the people, which is a total of 46 people, who answered YES, they have an intellectual disabled family member or they know someone that suffers from an intellectual disability. And the 24,6% of the people, which is a total of 15 people, answered NO.

This shows me that more than half of the Americans that answered the questionnaire know someone that suffers from an ID.



Graphic 9: Question 5, American questionnaire

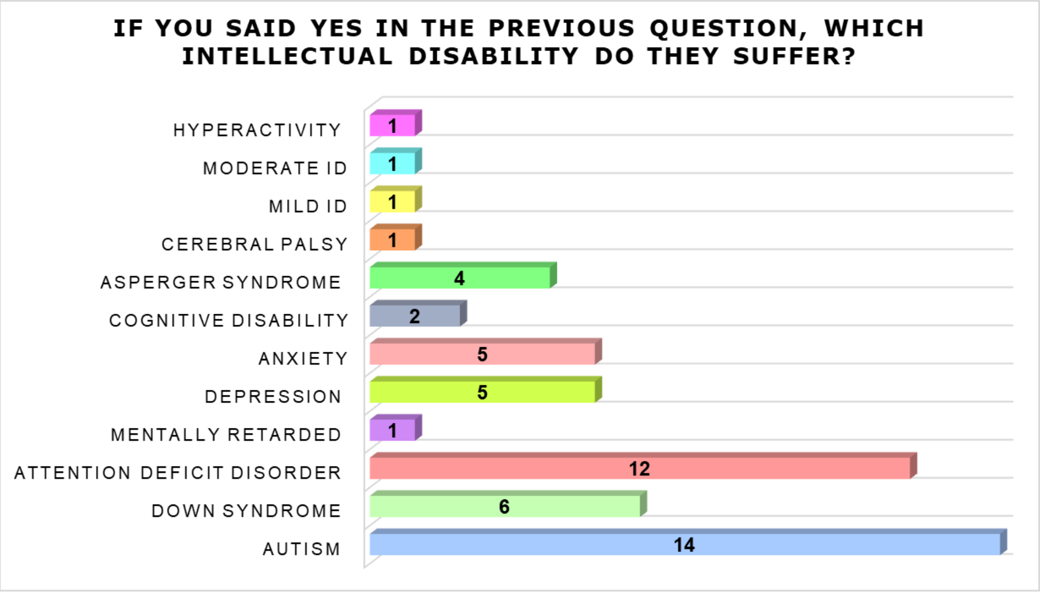
On the other hand, the Catalan questionnaire had pretty different results, as seen in the graphic below. The 36,6% of Catalans that answered the questionnaire, which is a total of 67 people, answered Yes, they know someone or have a family member that suffers from an intellectual disability. To my surprise, the 63,4% of the Catalans that answered the questionnaire answered No, they do not know anyone that suffers from an intellectual disability.



Graphic 10: Question 5, Catalan questionnaire

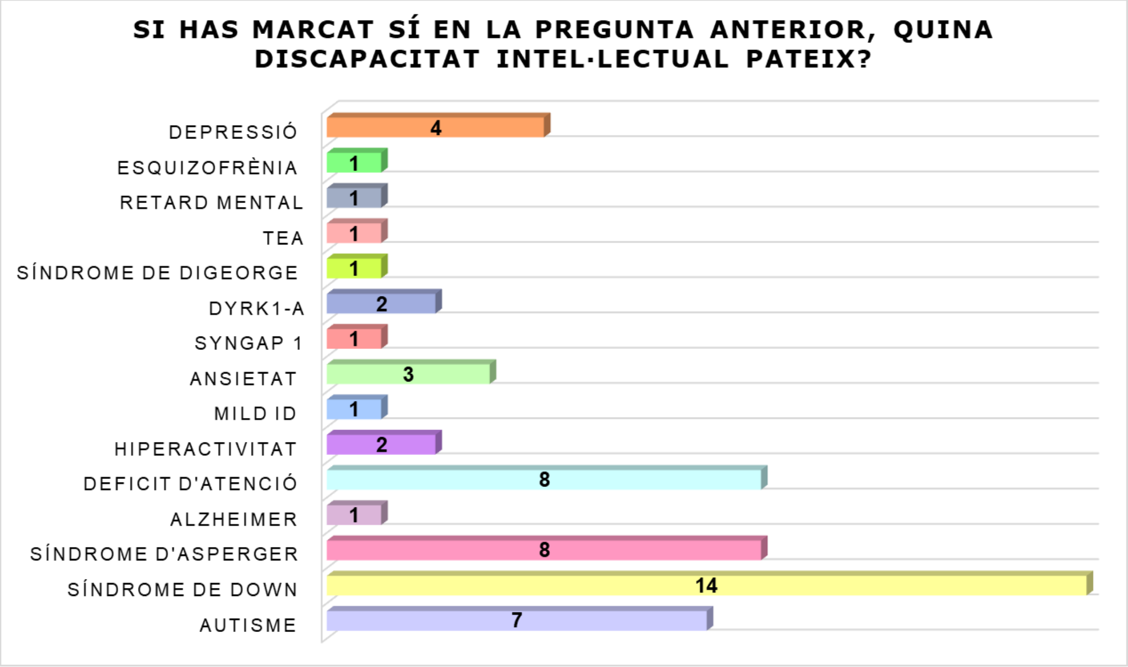
After getting these results, I asked the people that were answering the questionnaire to write the name of the intellectual disability the person that they know suffers from, only to the people that had answered “Yes” in the 5th question. I was surprised when I saw, in both questionnaires, people saying that the intellectual disability that the person they know suffers from is Anxiety, Depression or attention deficit disorder. That really showed me the lack of information that society has on this topic.

In the American questionnaire the 41 people that gave an answer to this question, ended up naming 12 different intellectual disabilities or mental disorders. There was one person that wrote hyperactivity as the answer, which is not an intellectual disability but a mental disorder. Someone else wrote cerebral palsy, which is not an intellectual disability either. Five people said that they knew someone that suffered from anxiety, and five other people answered depression, which neither of those are intellectual disabilities. Twelve people said that they knew someone that has an attention deficit disorder, which is not an intellectual disability either. The other answers were intellectual disabilities such as Moderate Intellectual Disability, someone else that answered Mild Intellectual Disability, Asperger Syndrome, cognitive disability, mentally retarded, Down Syndrome and Autism.



Graphic 12: Question 6, American questionnaire

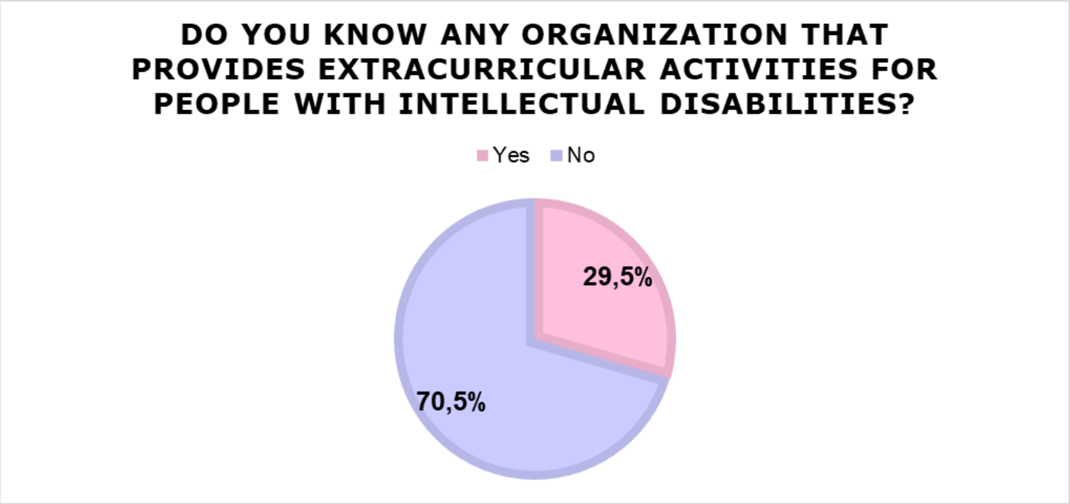
Looking at the Catalan questionnaire and its answers, the 63 people that answered question number 6 named 15 intellectual disabilities, mental disorders or illnesses. The people that were confused and answered mental disorders or illnesses, named the following ones: depression, Schizophrenia, DiGeorge syndrome, Anxiety, Alzheimer, hyperactivity and attention deficit disorder. The other answers were intellectual disabilities such as Mentally Retarded, TEA, SYNGAP 1, DYRK1-A, MILD Intellectual Disability, Asperger Syndrome, Down Syndrome, and Autism.



Graphic 11: Question 6, Catalan questionnaire

Once asked this, I was really interested in finding out if the people answering the questionnaire knew about any organization that helps people that suffer from an intellectual disability to do extracurricular or afterschool activities. The seventh question asks the people if they know any organization that provides these activities. They could choose between “Yes” or “No”.

In the American questionnaire, there was a 70,5% of the people that answered the questionnaire, which is a total of 43 people, chose “No” as the answer, and the 29,5% of the people, which is a total of 18 people, who chose “Yes” as an answer.



Graphic 13: Question 7, American questionnaire

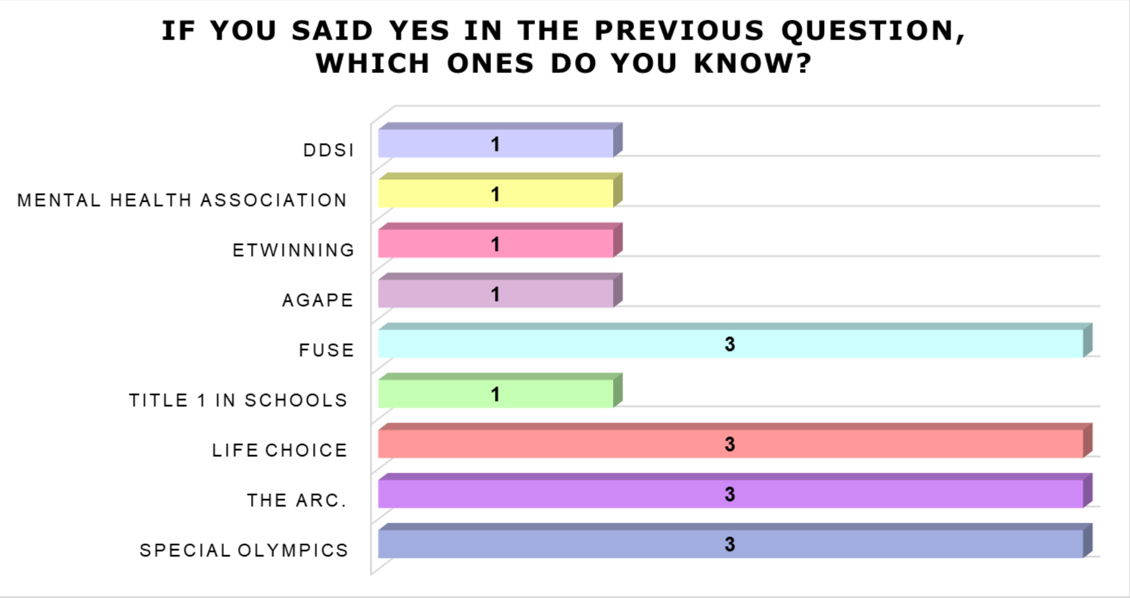
On the other hand, the Catalan questionnaire had pretty similar results, the 62,3% of the people that answered the questionnaire, that is a total of 114 people, answered “No” and the 37,7% of the people that is a total of 69 people, chose “Yes” as the answer.

Graphic 14: Question 7, Catalan questionnaire

This also shows the lack of information and involvement that there is in the community as there are a lot of people that do not know, and are not involved in the special needs world and the intellectual disabled word.

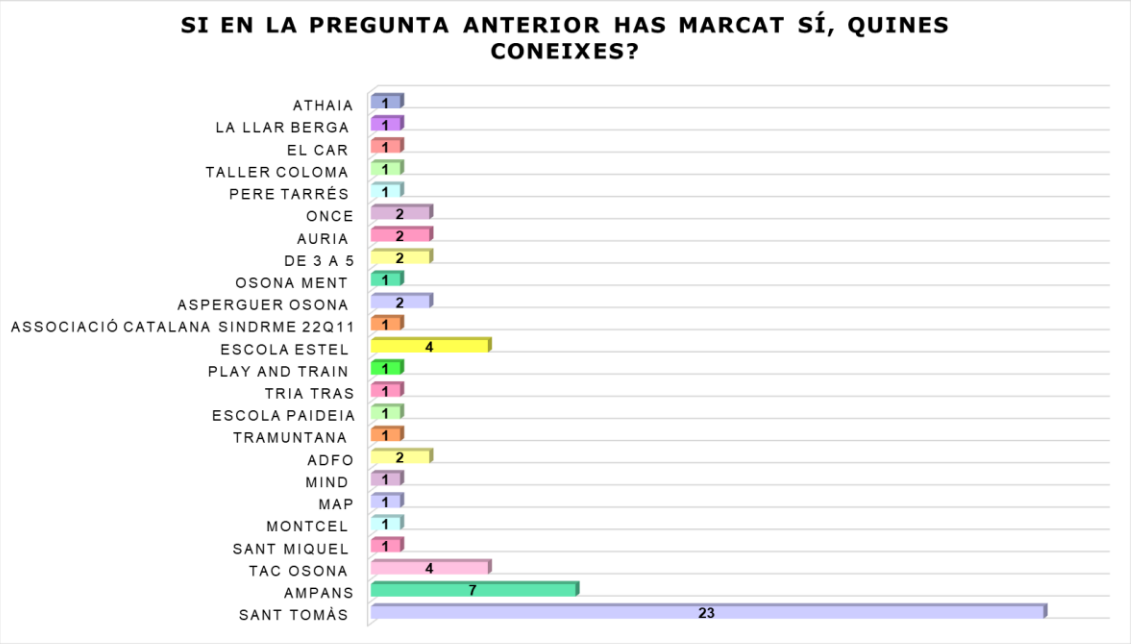
After asking this question I asked to the people who answered “Yes” in the previous question to name one or more organizations that they know. I was surprised to see that there were lots of different organizations that people knew.

In the American questionnaire, I got 22 answers from the people, and they named a total of 9 different organizations. Three people named Special Olympics, three other people named The Arc., there were 3 more people that said Life Choice, one person that named Title 1 in schools. Three other people that named FUSE, one person that named Agape, another person that named eTwinning, another person that named the Mental Health Association and finally one other person that named DDSi.



Graphic 15: Question 8, American questionnaire

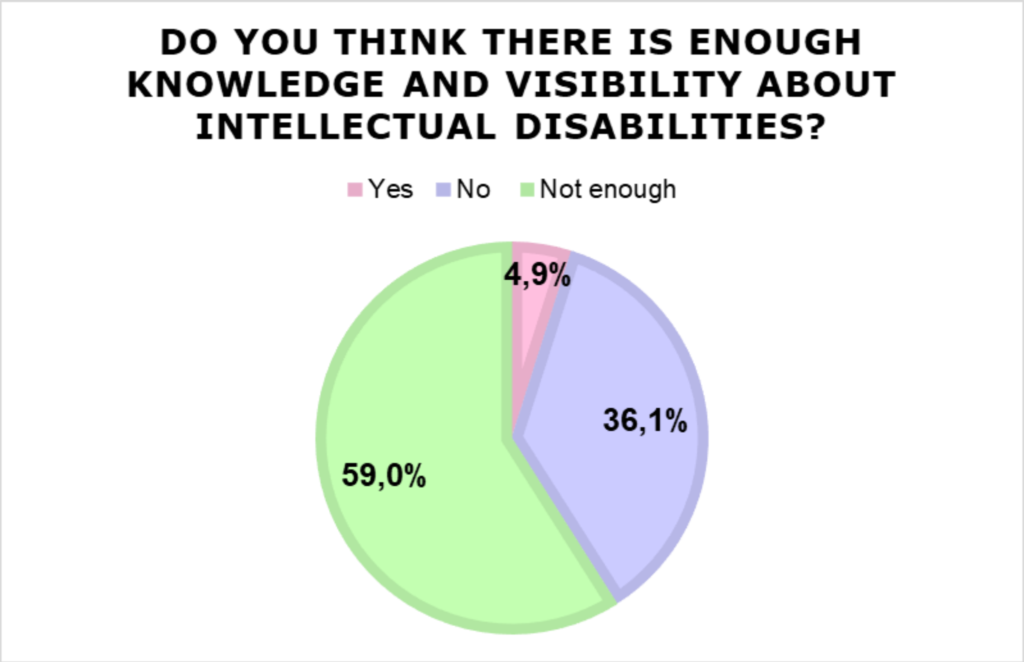
On the other hand, in the Catalan questionnaire, I got 59 answers and the people that answered named 24 different organizations, which are the following ones: “Sant Tomàs, Ampans, TAC Osona, Sant Miquel, Montcel, MAP; Mind, ADFO, Tramuntana, Escola Paideia, Tria Tras, Play and train, Escola Estel, Associació Catalana de Síndrome 22q11, Asperguer Osona, Osona ment, De 3 a 5, Àuria, Once, Pere Tarrés, Taller Coloma, El Car, La Llar Berga and finally Athaia”.



Graphic 16. Question 8, Catalan questionnaire

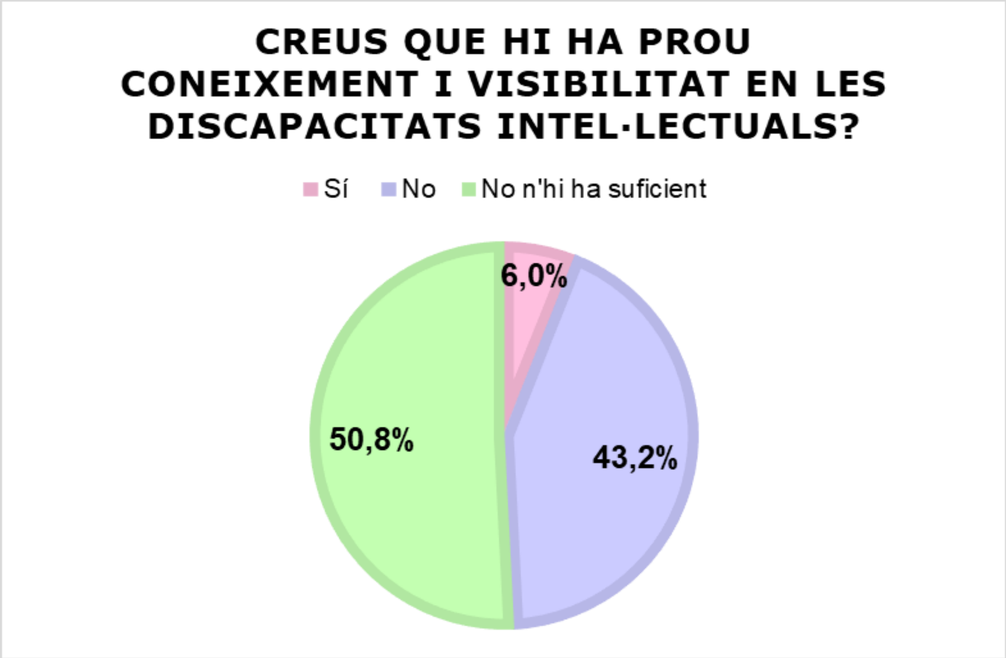
And the last question of the questionnaire was: “Do you think there is enough knowledge and visibility of intellectual disabilities?”. As the answer of this question, they had three options, the first one was “Yes”, the second one was “No” and the third one was “Not enough”.

In the American questionnaire there was the 59% of the answers, which is a total of 36 people, that voted “Not enough”, the 36,1% of the answers, which are a total of 22 people, chose “No” as the answer, and finally, the 4,9% left, which is a total of 3 people answered “Yes”.



Graphic 17: Question 9, American questionnaire

On the other hand, in the Catalan questionnaire, the conclusion of this question and its results were pretty similar to the American questionnaire. The 50,8% of the answers, which is a total of 93 people, choose “Not enough” as the answer, the 43,2% of the answers, which is a total of 79 people, answered “No”, and the 6% left of answers, which is a total of 11 people, said “Yes”.



Graphic 18: Question 9, Catalan questionnaire

Once I got all the results, I came up with some conclusions.

I have seen that there are more people in America involved in the special needs and intellectual disabilities world and also there are more people that have a close person who suffers from an intellectual disability in America, but this does not make a big difference when asked if they knew any organizations that help these people to do activities in order for them to have fun or learn daily basis things. I was also surprised when I saw that in both countries, the people confuse intellectual disabilities with mental disorders, even though I was already expecting a great number of people to get confused and mix both disorders.

At first, when I sent this questionnaire, my hypothesis was that the American people would have more knowledge about intellectual disabilities and be more involved in the special needs world, but not both things ended up being true. I was right in the first part, Americans have a little more knowledge about this topic than Catalan people, but as a difference of my hypothesis, the involvement is not significantly different in both countries. There is not enough involvement into this intellectual disabled world. What also surprised me a lot, was the fact that the Catalan people knew a larger number of organizations that help intellectually disabled people. At first, I thought that the Americans would know more organizations.

Both Catalan and American people concluded that there is little knowledge and visibility on this topic but it is not enough. There should be more information in order for the society to know how to live life with all the intellectual disabled people in the general daily basis, in order for everyone like a normal life together.

As conclusions of this comparison, I would say that Americans have a little more knowledge than Catalan people on this topic, but there is enough knowledge and visibility neither in America or in Catalonia, which means that it is still needed information and it is going to be long way until there are enough things, people or information about and for these people, the intellectual disabled people, and it is also going to be hard to be able to introduce the people who suffer from an intellectual disability to normal life, daily bases, and activities with all the typical developed people without them getting treated differently.

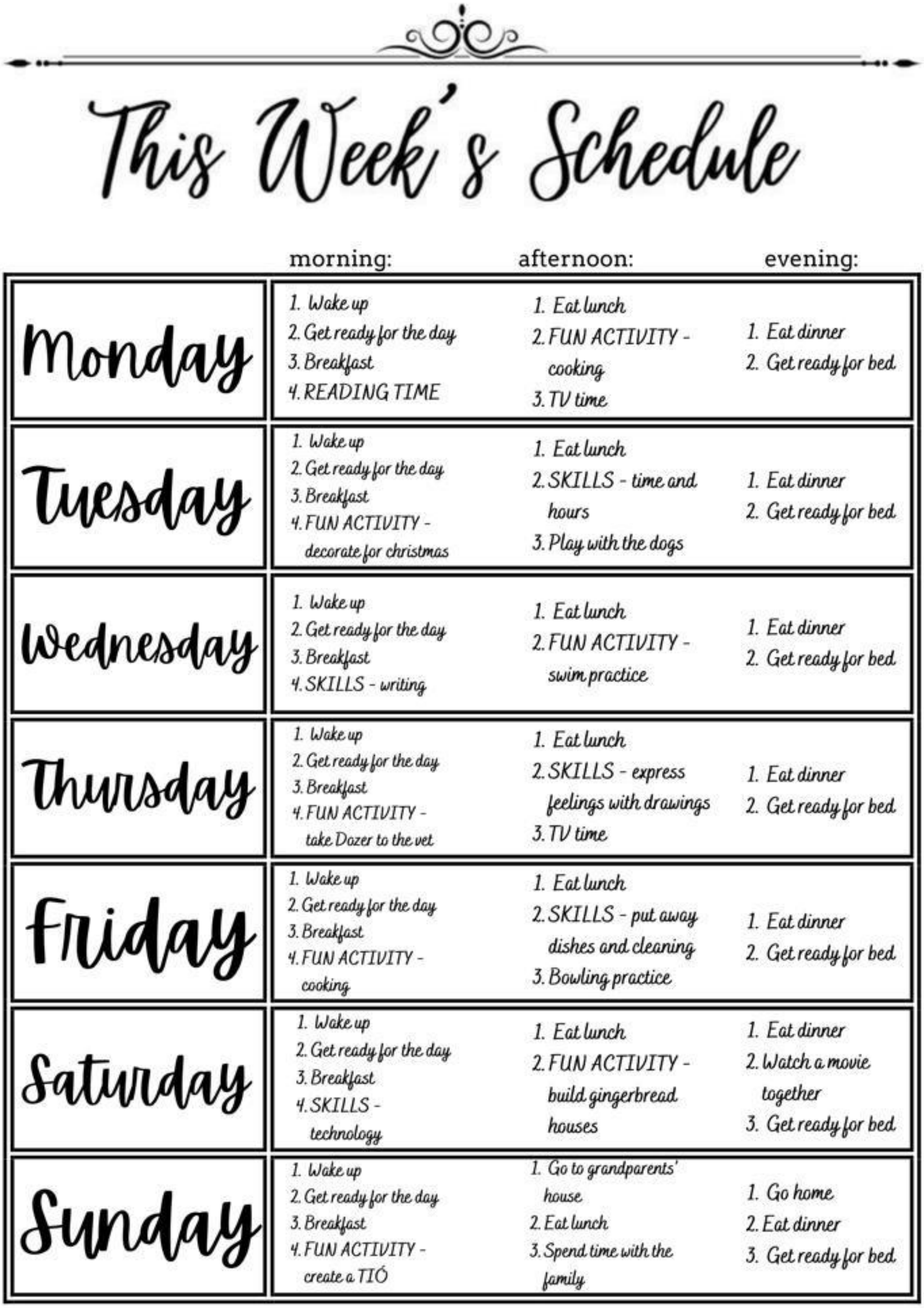
11. WEEKLY PLAN FOR AN INDIVIDUAL WITH MILD INTELLECTUAL DISABILITY.

Quincy Kopp, is an 18-year-old girl with Mental Retardation – high functioning clinical diagnosis. She has American Citizenship and Quincy lives in the state of Indiana with her dad, Jason Kopp, her mother Christy Kopp and her younger sister Jalyn Kopp. She graduated high school the school year of 2021-2022. Quincy loves animals, do crafts, do puzzles and paint.

The second part of my practical part consists of preparing a weekly plan for a teenager that suffers from an intellectual disability. I decided to make the plan for a week during Christmas break, when Quincy, my American host sister, did not have school, in order for her to keep up with daily basis activities and do not lose the habit of following a schedule.

During one week of Christmas break, I prepared activities for her and helped her with those activities, the activities were either basic things that she is going to have to do when she gets older in a daily basis, such as cooking or taking care of her dog, and school activities like reading or expressing her emotions drawing or writing.

Before seeing the schedule and the explanation of the activities, it is necessary for people reading this project to know that Quincy is an 18 years old teenage girl who has a 9 years old mentality and a Kindergarten level when it comes to reading and writing, and easy things in the daily basis such as identify what time it is, are really hard for her.



This Week's Schedule

	morning:	afternoon:	evening:
Monday	1. Wake up 2. Get ready for the day 3. Breakfast 4. READING TIME	1. Eat lunch 2. FUN ACTIVITY - cooking 3. TV time	1. Eat dinner 2. Get ready for bed
Tuesday	1. Wake up 2. Get ready for the day 3. Breakfast 4. FUN ACTIVITY - decorate for christmas	1. Eat lunch 2. SKILLS - time and hours 3. Play with the dogs	1. Eat dinner 2. Get ready for bed
Wednesday	1. Wake up 2. Get ready for the day 3. Breakfast 4. SKILLS - writing	1. Eat lunch 2. FUN ACTIVITY - swim practice	1. Eat dinner 2. Get ready for bed
Thursday	1. Wake up 2. Get ready for the day 3. Breakfast 4. FUN ACTIVITY - take Dozer to the vet	1. Eat lunch 2. SKILLS - express feelings with drawings 3. TV time	1. Eat dinner 2. Get ready for bed
Friday	1. Wake up 2. Get ready for the day 3. Breakfast 4. FUN ACTIVITY - cooking	1. Eat lunch 2. SKILLS - put away dishes and cleaning 3. Bowling practice	1. Eat dinner 2. Get ready for bed
Saturday	1. Wake up 2. Get ready for the day 3. Breakfast 4. SKILLS - technology	1. Eat lunch 2. FUN ACTIVITY - build gingerbread houses	1. Eat dinner 2. Watch a movie together 3. Get ready for bed
Sunday	1. Wake up 2. Get ready for the day 3. Breakfast 4. FUN ACTIVITY - create a TIÓ	1. Go to grandparents' house 2. Eat lunch 3. Spend time with the family	1. Go home 2. Eat dinner 3. Get ready for bed

Picture 33: Weekly Schedule, Christmas week – self created

During one of the weeks that my sister and I were on Christmas break, I asked my host mom to be the “staff” of my host sister and help her with the skills that I saw she worked on with her usual staff, in order to do the practical part of my project. She let me do it and I created this schedule, basing it on the activities that she already had scheduled such as practices. Once I had the schedule done, I asked my host mom and Quincy’s staff for their opinion about the schedule and they said it was a perfect schedule for Quincy’s needs. So once the week began, I started to work as her staff.

The schedule is based on 4 activities during the morning, then 2 or 3 activities in the afternoon, and 2 activities in the evening, except for some day that we did some activities together to have fun and built a better relationship.

The first part of the day was the same for all weekdays and weekends. It is for this reason that it is just written on Monday.

This schedule goes from Monday to Sunday.

<u>Monday</u>

On Monday, she had to wake up at 8 AM, make her bed, and get ready for the day, which included changing her pajamas into the clothes that she wanted to wear that day, brush her teeth, brush her hair, put on deodorant and put on her shoes. After that, she came downstairs and prepared herself breakfast. She usually eats toasts with peanut butter, milk and some type of fruit, so she would toast a slice of bread, add the peanut butter or chocolate cream, whatever she wanted, and put milk into the glass. Once she had finished that, if she was still a little hungry, she also prepared herself fruit, which was already cut in the fridge.

Picture 34: Example of the papers I prepared to Quincy with easy words to read

After she had eaten breakfast, we started working on her reading skills, I had prepared some papers with easy sentences or easy words, with pictures that could help her and try to read those words or single sentences. It was really hard for her, and she got tired, collapsed, distracted and would want to stop, that is why we stopped every once in a while, in order for her to rest and then we came back to the work. When we stopped and got some rest, she went and played with her dogs, fed and watered them and then explained me something exciting for her. After that, she was ready to go back to the reading lessons.

When we finished our reading activity, we went to the kitchen and had lunch, which her mom had done while we were working. And then she wanted to get some rest and watch TV for a while, so we laid on the sofa and watched a series that she loves. After having been watching TV for an hour, it was time to do the FUN ACTIVITY of the day. On Monday, the fun activity consisted of cooking. We baked a chocolate brownie, she had to prepare all the ingredients that we needed to bake the brownie and then she decided that she wanted to put some nuts on the brownie in order to have a better flavor, and that was a clever move. Once we baked the brownie, it was dinner time, so we sat down and ate dinner with the whole family, and after dinner it was time for all of us to try the desert that Quincy had baked. It was really good and that made her feel like a real cook. She was really proud of herself and the result.

Picture 35: Quincy making a brownie

Then she went and got ready for bed, this included showering, brushing her hair, doing her skin care routine, changing into her pajamas, brushing her teeth, and going to sleep, as she had to do every day.

Monday was a really successful day for Quincy.

Tuesday

Once she had eaten breakfast, I had prepared a FUN ACTIVITY for her. Since it was Christmas break and the Christmas tree that we had in our house was not finished, we spent the morning decorating the tree and finishing to decorate the house for Christmas. She had a wonderful time decorating the tree while listening to Christmas music, and she was really proud of the final result. She asked me the whole time to see if where she had put the Christmas ornament was okay, and while decorating the tree, we worked on being careful when grabbing objects that could break easily.

Picture 36: Quincy and I decorating the Christmas tree

After decorating the tree, she was really hungry so we went to the kitchen, and had lunch together. During lunch time, we worked on skills such as lay the table, be careful with the knife, and put away the table.

Once we finished eating lunch, it was time to start working on the skills of the day. On Tuesday we had to work on the time and how to interpret and know what time it was. That was a pretty challenging thing for her, because she would try to say the time and she would always add a zero, for example if the phone's screen said that it was 4:45pm, she had to say all the numbers that appeared on the screen and she would say 4, 0, 4, 5, and when I asked why she said zero and where she saw it, she affirmed she did not say any zero, and that showed me that she got really confused while trying to say what time it was.

Picture 37: Quincy playing with Dozer

After an hour and a half working on numbers, time and hours, it was time to get some rest so we went and played with the dogs. She enjoyed the time that we spent with the dogs a lot and you could see she was more relaxed and happier.

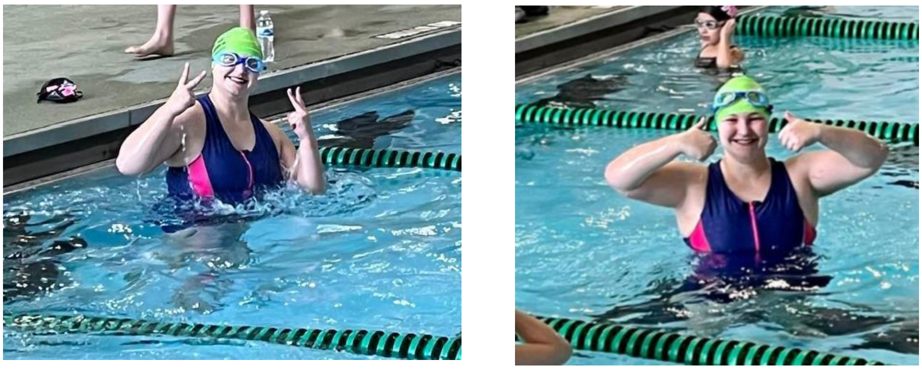
Once we had been playing with the dogs for a while, we went to have dinner and it was time for her to get ready for bed, this included showering, brushing her hair, doing her skin care routine, changing into her pajamas, brushing her teeth, and going to sleep, as she had to do every day.

Tuesday was a productive day for Quincy and she went to bed really happy.

<u>Wednesday</u>

After she had eaten breakfast, we started working on her writing skills. We had all the letters of the alphabet and we took a look at every letter in order for her to remember how to write all the letters. Then she had to write simple words such as her name, because as I said before, she has a kindergarten level, so it was like working with a little kid who was just beginning to learn how to write. After a while working on writing, she was saturated and wanted to take a break, and that is what we did, so we went to have lunch and after eating lunch, we relaxed for a little on the sofa.

Picture 39: Quincy's writings



Picture 38: Quincy at swim practice

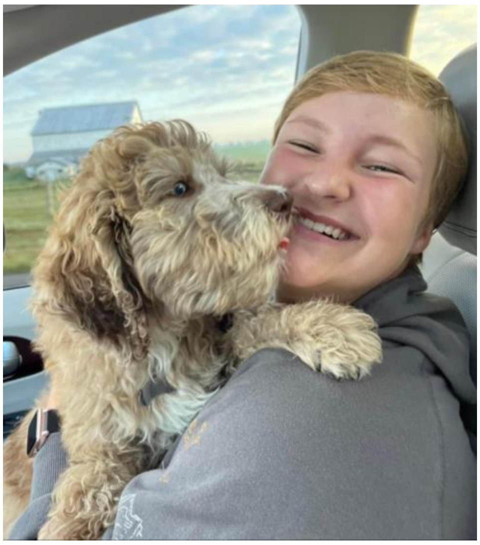
After a while, we went upstairs to her room and I helped her to get ready for swim practice, we worked on packing everything that she needed, grabbing some snacks and filling up her bottle of water. Then we left to swim practice, where she spent 3 hours. I stayed at the practice with her mom, who drove us there, and we watched the whole practice.

When she finished, we went home, and it was late so we had dinner, and she went upstairs to get ready for bed, which included showering, brushing her hair, doing her skin care routine, changing into her pajamas, brushing her teeth, and going to sleep, as she had to do every day.

Wednesday was a tiring day for Quincy but she had a lot of fun.

<u>Thursday</u>

Quincy was really happy and excited to do the activity that we had planned for the morning. My host mom had to take Dozer, Quincy's dog, to the vet, and as Quincy loves animals and she needs to learn how to take care of them, we went with her to the vet and Quincy learned a lot of different things about dogs and how to train them. She was really excited and could not stop smiling, she was really interested in what the vet was teaching her.



Picture 40: Quincy and Dozer

When we got out of the vet, it was earlier than what we had expected so we went to the grocery store to buy some ingredients so we could do another fun activity on the following days. There, Quincy worked on how to act responsible in public, how to manage money and what to do when going shopping is needed.

Then we went home and had lunch together. After that, it was time to work on our emotions, so I told Quincy to draw anything she wanted, and express her feelings in a free and funny way. We spent the whole afternoon painting and drawing and she loved it, she had a wonderful time and a lot of fun. While she was drawing, she was also being the DJ and putting music on!

Picture 41: Quincy's drawings

When we finished, we had dinner and she was ready to go to bed, so she went to get ready and do the activities that she had to do every day, which were showering, brushing her hair, doing her skin care routine, changing into her pajamas, brushing her teeth, and going to sleep.

Quincy loved Thursday and she was really happy when the day ended.

<u>Friday</u>

After eating breakfast, it was time to have some fun, so we started with the activity that I had prepared for the day. The activity was cooking, because she loves it and it is a good way to teach her lots of skills that she is going to need in the future. That day, we decided to bake some cookies, and we baked different types of cookies. We did everything from the beginning, and Quincy had to prepare all the ingredients and all the kitchen utensils that we needed. We made the cookie dough, and had to wait for an hour in order

Picture 42: Quincy and I making cookies

to start making the different shapes, so I asked and taught Quincy how to set the timer so it would warn us when it was time to take it out of the fridge and start making the shapes. Quincy also turned on the oven and when we finished making the shapes, we put the cookies in the oven, and Quincy set the timer, this time alone.

When we finished the cookies, we ate lunch, and after eating lunch, we cleaned all the utensils that we used to make the cookies and put all the dishes away. These are the skills that she also had to work on.

After putting all the dishes away, she laid on the sofa for a little before it was time for her to go to her bowling practice and when the time came, my host mom took us to her bowling practice, where she stayed for two hours. It was a really good practice for her, and she and two other team mates received an award for having a really good practice. She was really happy and proud.

Picture 43: Quincy at bowling practice

When she got out of the practice, she could not wait to get home because she wanted to taste the cookies that we had baked earlier that day, but when we got home, before tasting the cookies, we had dinner, and then she tasted the cookies, and she said those cookies were delicious.

After that, she was really tired, so she went get ready to go to bed and she did the activities she always had to do before sleeping, which were showering, brushing her hair, doing her skin care routine, changing into her pajamas, brushing her teeth.

She loved Friday and she was really tired, she had had a really good day.

Saturday


Picture 44: Quincy working on her iPad

After getting ready and having breakfast, it was time to start with the morning activity, which was working on her technological skills. We used her iPad, and she spent the morning doing different things, painting mandalas that had numbers associated with colors so she also worked on numbers. She played a game that consists of feeding and taking care of animals from a farm and she also played a game about doing puzzles. She had an awesome time because she did not notice that she was working on multiple skills while playing those games.

When she finished, we went to the kitchen and had lunch, and after eating lunch, we had an activity that was so much fun, we built gingerbread houses, an American tradition that they love doing during Christmas. It was a really funny afternoon because building those houses was way harder than what we had expected and we laughed a lot. She said that building those houses was so much fun and she loved it.


Picture 45: Quincy Building gingerbread houses

When we finished, it was almost time for us to have dinner so we went to help my host mom, who was making dinner and when it was finished, we had dinner all together.

After having dinner, and since it was Saturday, Quincy could stay up a little late so we decided to watch a Christmas movie all together, and when the movie ended, she went to get ready for bed and as always, she showered, brushed her hair, did her skin care routine, changed into her pajamas, brushed her teeth.

Quincy really enjoyed that Saturday.

Sunday

For that morning, I had a really fun and interesting activity prepared for Quincy, I wanted her to learn about the traditions that we have in Catalonia so I prepared everything that we needed in order to create a “Tió”. When I explained her the plan, she was really excited and she could not wait to start, so we spent all the morning making the “Tió” and also learning the song. She had a lot of fun and she could not stop asking about that tradition and things that she wanted to know. When I told her that we would have to feed it until Christmas day, she was really excited and she said she would be the one feeding it every day.

Picture 46: Quincy creating the “Tió”

Once we finished making the “Tió”, we got ready and left to Quincy’s grandparents’ house where we had lunch and spent the afternoon with the family.

Once we got back to our house, Quincy was really tired, but before going to get ready for bed, she did not forget to feed the new family member, and once he was fed, she went upstairs and got ready for bed, as always, she showered, brushed her hair, did her skin care routine, changed into her pajamas, brushed her teeth.

Being the “staff member” of Quincy for a week helped me understand better how difficult it is to face life when suffering from an intellectual disability. During that week, I had a wonderful time, and I learned how to see life from a different perspective. I could see how hard it is for the people suffering from MILD intellectual disabilities to live life as a typically developed teenager. When you ask them to do the most simple thing and they look at you asking for help because they do not know how to do what you just asked them, I could understand how stressful it is for a mom, dad or a staff member to see that she is trying as hard as she can but she is struggling to do that one thing that you have been teaching her how to do for the last hour, and how hard the people that suffer from an intellectual disability work in order to get better. It made me realize the effort level that they have and made me appreciate them much more than what I already did.

During this period of time, I could see some of the signs and causes that describe MILD intellectual disabilities. While being the staff of Quincy I identified the difficulties that she has when she needs to do any activity of the daily basis like cooking or cleaning. I could also identify the difficulties with reading and writing and the anxiety that those activities caused to her. She needed to stop and relax pretty often in order to not get nervous or anxious.

12. CONCLUSIONS

During many years, scientists have been studying intellectual disabilities to have more information about these disabilities. An intellectual disability is a lifelong condition and the most common developmental disability. These disabilities affect the functioning in two areas, the intellectual functioning and the adaptive functioning which affects the person's life a lot. When suffering from an intellectual disability, there are some skills that the intellectual disabled people have more difficulty in learning. These skills can be conceptual skills, practical skills and social skills. During the years, intellectual disabled people have been treated differently from typically developed people, and this has improved with the time. Anyway, intellectual disabled people are not yet treated like other people. These disabilities have had lots of names in the history and these names have not always been respectful. In the past, "mentally retarded" or "feeble minded" were some of the words used to make reference to people suffering from intellectual disabilities. This project focuses on the MILD Intellectual Disability, which is one of the most common IDs. People with MILD intellectual disability are slower in all areas of conceptual development, social and daily living skills, and that makes them have the need of having someone to help them all the time. The causes of the disability are not 100% found yet, and there are lots of researches going on in order to get more information about this type of intellectual disability.

In this research project, the main approach was to bring information about these disabilities to the people of Catalonia and comparing the knowledge that the people form Catalonia and the people from the United States of America have.

The first aim of the practical part of this project was to compare the knowledge that both Catalan and Americans have about these disabilities, which was achieved. My initial hypothesis was not totally true but partially, as I thought that Americans would have more knowledge about intellectual disabilities than Catalan people. The final conclusion of this comparison was that neither Catalans nor American have enough knowledge or give enough visibility to intellectual disabilities and, as I thought at first, most of the people confused intellectual disabilities with mental disorders.

The second goal was to give visibility and information about these disabilities to the people of my surroundings, and this goal was also achieved, as while doing the project lots of people of my surroundings became more interested in intellectual disabilities and wanted me to explain them what these disabilities are about.

As far as difficulties are concerned, I have found difficulties in founding information about this topic despite being a wide topic. Lots of documents that my host mother gave me provided a big part of the information of this project. Another difficulty was getting used to the vocabulary used in all the medical documents due to the technical language that was used, and that made me have to look up some words in order to understand what the documents were talking about.

The practical part was not as difficult but much more impacting in an emotional way, being the staff member of someone that suffers from an intellectual disability is really hard and it takes a lot of courage and emotional strength. These people have a hard time on their daily life and no one notices it, unless they dedicate their time to them and then you see how hard they work to achieve not even half of what we would say the “easiest” daily life activities. The strength and effort that my host sister has made me realize how brave she is and how hard she works to be as “normal” as possible, and made me see life from a different point of view.

I would like to conclude by saying that doing this research project has been one of the greatest experiences of my life and it has been an excellent way to enjoy myself, my host sister and all the special needs community during this past year. When I began doing this project, I was really interested in the topic but as I was progressing with the project, my interest increased much more.

13. CONTENTS: IMAGES, CHARDS AND GRAPHICS

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15. IMAGE WEBOGRAPHY

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