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MONOGRAPH

“How should be the treatment for a person with Down syndrome in society?”

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Gratitude

First, I want to thank God for the life and family that I have, because my family gave me education and opportunities to develop myself as a student and a person, thanks to them, and God again, I am progressing in my project of life to find the happiness. Then I want to thank my friends and teachers that supported me to remain hopeful to my wishes.

Summary

In this work you will learn more about the most famous and more common Syndrome in the world, this syndrome is known as Down syndrome. First, you will receive information about the origin of this Syndrome. Then you will learn or recapitulate how this Syndrome affects the life of the people who suffers from it. Something important that this work talks about and you would find interesting it's the fact that the persons who have Down syndrome are more kind than other people and they are underestimated by others only for their looking. So you will find more about the diseases that this genetic condition could produce in the bodies of people who have this syndrome, the most common type of disease that they would experience are related with heart problems. Then it comes the information about the mental problems that they could develop, all this depends in how the genetic condition affects the person or how it is the treatment that they receive. When this work talks about the treatment, it's talking about the social and medical treatment that they are receiving constantly and how it would be better for them if they received a better social treatment and, the objective of this work is to recognize how it should be the treatment to a person who has Down syndrome. The problem here it's that many people don't know about the things that a person with Down syndrome thinks and they don't know how they will react to determinate type of situations. Finally, this work shows you recommendations about the treatment that they need from you, and how you can help to make them feel better, cause' they are humans too., and sometimes more human as us. So if you read all this work you will have a better knowledge about the Down syndrome in a theoretically and socially way.

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Introduction

The following monograph talks about information of the Down syndrome and how should be the treatment for a person with Down syndrome in society. The importance of this it's too recognize how different it's the life of a person with Down syndrome, to know the origin of this condition, and principally to know how to treat them correctly, because many people don't know that they understand perfectly the things that we are trying to communicate to them, that they sometimes feel confused by the treatment that they received.

The things that justify this study are that there are many people who suffer from this popular condition, known as Down syndrome. So maybe one time in our human life, people would need to communicate with a person that has Down syndrome or any other condition, so then people should know how to treat them correctly, they should not be afraid to talk to them or anything else.

There are a lot of studies about Down syndrome, but if the study is about social treatment that they usually receive we can find specific ones that relate perfectly the treatment that they receive constantly, good and bad, and how they felt after the dialogue experience. All this studies were doing from people who want to show the world the reality of the society to this kind of people.

So, why people should know how to treat them? People should know because this topic will not exist if there is not a problem, the problem or cause here it's that many people, who don't know how a person with DS think, treat them sometimes in an awkward way and sometimes this strange way of treatment transforms into an aggressive treatment that disrespect the

condition that this type of person suffers, there is when sometimes the bullying appears as a consequence of the ignorance.

This monograph is divided in 4 chapters, the first chapter talks about the Down syndrome profile, their characteristics that are divided in 2: psychological and physical. Then the second chapter talks about the Down syndrome in general, his definition, causes and consequences. Then the third chapter talks about capacity of a person with DS, that is divided in two: social and physical. Then the final chapter (number 4) talks about the treatment that the received, there is two type of treatment in this chapter: the social, that it's divided in the treatment from the family and the treatment from other people; and then it's the medical treatment.

Chapter I

Down syndrome profile

1. Characteristics

1.1 Psychological.

The Down syndrome produces a lot of changes in the form of thinking in a person who have it, but not all the people who have this type of syndrome think in the same way, of course they have similarities but like every person in this big world, they think in his own special way. So there is the interest of the people that investigates these types of anomalies and the reactions that they cause to people.

Many people don't know how a person with Down syndrome reacts to specific situations `cause they think that a person with Down syndrome can't understand the things that we are trying to say to them, so there is the social problem that I'm going to talk later.

This type of people with this condition, in a part of their life, suffers from depression that other people or situations could cause it. How Danés (2012) declares: ``Depression is difficult to diagnose in people with Down syndrome as its symptoms can be mistaken with those of other conditions. Importance is also placed on prevention'' (párr. 2).

They are much known for being kindly, open and funny persons. They loved to interact with other people in their own way, using physical contact and natural gestures. For my experience, this type of communication that they have makes me feel happier and it's a reality for other people that feel the same like me. I enjoy to interact to this kind of persons and they like it too `cause they only try to see the good in a person, they are affective persons.

1.1.1 Mental problems.

The Down syndrome affects the mind of the people who have it, we already know that but the fact is that it comes with different mental problems. The mental problems can vary depending on the person and their thoughts. If a family member wants to be sure of the

mental health of the person with the Down syndrome, they should visit a Down syndrome specialist.

The DS specialists will help their DS patients with a good diagnosis and control of their mental health in association of a psychiatrist.

The mental problems that a Down syndrome could have will be: Depression, schizophrenia (not very common), bipolarity, attention deficit hyperactivity disorder, Oppositional defiant disorder, different types of dementia, etc. All this mental problems are not very common but they are possible for each person that has this syndrome.

There are studies that say:

Behavior problems of 44 children with Down syndrome between the ages of 6 and 15 and 44 controls without mental retardation matched for age, sex, and socioeconomic status were compared on the basis of mother and teacher ratings. Ratings from both sources indicated that children with Down syndrome had more behavior problems, in particular attention deficit, noncompliance, thought disorder, and social withdrawal.

(Coe et al., 1999, p. 149)

So you can't say that a kid, teen or adult with Down syndrome is going to have a determined mental problem for this information, but yes, it's possible. One principally thing that a professional analyzes for make a diagnosis is the behavior of the patient with Down syndrome and the symptoms that the patient has.

1.2 Physical.

An easy way to recognize a person with Down syndrome is looking at his face, because they have a particular formation of their heads and facial features that other conditions don't always present. This syndrome is so known in the world that most of the adult population can recognize it only seeing them at the face, one reason of this could be that this syndrome is so common that people (most of them kids) ask other people that why are they different

and what do they have, so they received their answers and then they can recognize a person with Down syndrome in a future.

For these facial features is why people (not all of them of course) in many cases treat them in a bad way but I'm going to talk about that later in the social treatment.

As vary experts affirm:

This band (band q22) has been called the "Down syndrome region", as defined by the presence of a subset of the major phenotypic features of the syndrome. These features include mental retardation, congenital heart disease, the characteristic facial appearance, and probably the hand anomalies and dermatoglyphic changes.

(American Journal of Human Genetics, 1990, p. 236)

So we can say that the Down syndrome entails so many unique features that we can easily recognize the phenotypic that it involves with our own eyes.

1.2.1 Health problems.

The Down syndrome involves various health problems that affect the style of life of the person who have it. The more common health problems are heart defects, nearly the half of persons with DS have heart defects that could vary; vision problems, nearly the sixty per cent have vision problems; hearing loss, around seventy per cent to seventy five per cent have hearing loss, normally for the structure of the ears; diseases of the blood, as leukemia, anemia and polycythemia; and many others.

A person with DS needs a special care for his health, the help of his family is essential and the good diagnosis of a professional that help with the health problems of a DS.

Physical activities are a good example for help the person with DS. Normally the activities that persons with DS do for their health are: swimming, bowling, dancing, team sports, and walking. So they should practice these activities for a better condition if their doctors recommend it.

So it should be mentioned that: ``It is reasonable, however, to assume that acute health problems might present barriers to physical activities for youth with DS and that, when medical issues are efficiently overcome, physical activities may be facilitated'' (Pitetti, Baynard, Agiovlasitis, 2013, p. 53).

In conclusion, there is so many health problems that a person with DS could have but these problems can receive a treatment from a specialist that would contain physical exercises and other kind of things.

Chapter II

Down syndrome

2. Definition

Many people make a mistake when they called Down syndrome as a disease or illness, cause it is not. Simply Down syndrome is an anomaly that many people suffer when there is an extra copy of the chromosome 21.

How many experts confirm:

Down syndrome is a major cause of mental retardation and heart disease.

Although it is usually caused by the presence of an extra chromosome 21, a subset of the diagnostic features may be caused by the presence of only band 21q22. We now present evidence that significantly narrows the chromosomal region responsible for several of the phenotypic features of DS.

(American Journal of Human Genetics, 1990, p. 236)

We cannot say that Down syndrome is an illness, but we can say that it provokes many heart diseases and many physically changes in the body, especially in the face.

Many people do not know what Down syndrome means and if their future kids would have it. So there are many studies of the probabilities of having a baby with this syndrome, but until now the Scientifics do not know why this happens. The possibility increases when a woman gets older and if a woman already has one child with Down syndrome, the next one will have a 1 percent of probabilities of have it, only if the mom is over 40. There is a risk factor too that says that a 25 years old woman has 1 in 1200 of having a baby that will suffer this syndrome, if the woman is 35 years old it would change to 1 in 350, if she is 40 it would be 1 in 100 and finally if she is 49 it would be 1 in 10 of probabilities of having a child with Down syndrome.

There is another theories about the probabilities, how this scientific said: ``Use of the difference between observed and expected nuchal fold thicknesses to determine likelihood ratios allows the calculation of individual posterior probabilities of Down syndrome that take

into consideration both gestational age and maternal age'' (Am J Obstet Gynecol 2000, p. 182:192-7.)

2.1 Causes.

First of all, Down syndrome is one of the most common causes of congenital anomalies. So we can say that it is a very common condition that people can observe and interact with it outside or inside their houses. Most of the people, probably, have a familiar with Down syndrome or they could have one in a future.

For that reason, scientifics investigated this popular condition with many professional studies, they did those things principally with the purpose of finding an answer to: Why some people born with this condition and why is it so common? Finally, they arrived with the conclusion

that Down syndrome occurs when there is an extra copy of chromosome 21. This form of Down syndrome is called trisomy 21. The extra chromosome causes problems with the way the body and brain develop. That is the answer for that questions.

People, after that conclusion, thought in other reasons, how Patterson (1987) mentions: "For years Down syndrome was a disease of unknown origin, seemingly random in its occurrence. Many theories were proposed, including ones that linked babies who had Down syndrome to endocrine-gland malfunctioning or to tuberculosis or syphilis in the parents" (p. 52).

So in conclusion, Down syndrome is cause by a random process when chromosome 21 has an extra copy, it is not cause by many diseases that a parent could has and it is not contagious.

The real thing is that this condition provokes another diseases that are related with mental and health problems that a person with Down syndrome could have. If parents want to prevent this condition for their children is possible but it takes a lot of hard process and probabilities.

2.2 Consequences.

If we think a minute, we can realize that only an extra copy of the chromosome 21 can make a lot of changes in our bodies, in this case, the Down syndrome. This syndrome is related with a lot of mental and health problems that can be treated by specialists. The consequences that most of the people can see and hear are the phenotypes and the way of expression that a person with Down syndrome has.

People with Down syndrome may also have delayed language development and slow motor development, which is the ability to use their muscles. But the more common health problems that a person with Down syndrome could have are heart diseases. Many of this people that have Down syndrome could suffer from depression for many different reasons.

One consequence would be the social treatment that this kind of people received, they are not treated as well as they deserved, they are friendly and funny persons who have a strong affection to know new people, but regrettably a lot of people keep thinking that they are people who do not understand nothing that you are saying to them or people talk to them in a strange way that make them feel bad and questioned.

So another consequence would be the behavior that many persons with Down syndrome present, as an expert mentioned:

Features cited with regularity include affectionate nature, even temper, and propensity to imitation. Behavior problems of children of school age with this syndrome have also been examined in some depth over the last 50 years. On average, one quarter to one third are reported as having significant emotional and conduct problems, with noncompliance, aggression, and hyperactivity most prominent.

(Journal of Autism and Developmental Disorders, 1999, p. 149)

In conclusion, this syndrome brings a lot of bad consequences that include health and mental problems accompanied with different types of diseases as heart problems and depression.

There is the social treatment that this kind of people receives as consequence of their condition. Their behavior is very special so people should tolerate and love it, because people with Down syndrome are so kind with new people, they sometimes feel bad cause the treatment that they sometimes receive but they keep seeing the world in a completely different way as other people.

Chapter III

Capacity of a person with Down syndrome

3. Skills

Many people think that a person with genetic problems and conditions like this syndrome cannot have or develop certain types of skills like a normal person without this type genetic problem could have, it is not that a person with this type of conditions cannot develop certain skills, it is a fact that a person who suffers from conditions like this has more difficulty to develop them and it takes a longer time, people and them must be patient if they want a good result.

The form of learning in a child with Down syndrome it's different than others, so it's necessary to change the approach if they want to get good results. It's important to help the parents to understand how and in which way their children with Down syndrome are learning.

A child with Down syndrome needs little portions of information; they cannot process extent information because they could stagnate in one part.

As a parent it's too important to understand that having a child with Down syndrome is not an excuse to justify the lack of education and skills in the child. A person with Down syndrome educates as anyone.

3.1 Social.

Normally, a person who has Down syndrome has social problems but all of those problems would be solved with a good education, patient and a lot of time. The parents must find ways to teach their children better communication skills if they want that their children have a good behavior.

As experts mentioned:

The more limited a teenager's expressive language ability, the more likely he or she is to have behavior difficulties. The implication here is that at least some difficult behaviors are the teenager's way of communicating when he/she does not have the language to do so.

(Down Syndrome Research and Practice 9(3), 2006, p. 60)

So if a teenager with Down syndrome does not know how to communicate one thing to someone his behavior would be affected by his actions.

The most important things for cognitive and social development are speech and language development because learning sentences and different words are the way to develop the mind of child and teenagers with Down syndrome.

It's like an expert affirms: "In addition, speech and language skills influence all aspects of social and emotional development – the ability to negotiate the social world and to make friends, share worries and experiences and be part of the family and community" (Down Syndrome Research and Practice 9(3), 2006, p. 60).

Going back with the behavior, a difficult behavior could affect the social opportunities and process of learning; this could affect the teachers and families in bad way like making them feeling stress.

In conclusion, the social development for a person with Down syndrome needs help from the family and people around them, because they need to feel that they are accepted and they need to learn when and where doing something it's wrong. Yes, it will be hard but with the time will be worth, so the parents must not forget that they should be patient and hopeful that their children would develop in the best way.

3.2 Physical.

Although this part talks about physical skills, it's worth say that the sports are a fantastic and wonderful method of social integration and promote healthy habits.

So now, it's know that everyone should do exercises and practice at least one sport as a good habit; this is not an exception for persons with Down syndrome. Persons with Down syndrome can develop their physical skills in different ways and they should do it for a better health, for the reason that some of them suffer from heart problems and diseases cause by the syndrome.

The sports are the best way to develop their physical skills, some sports are better than others because the benefits are better, for example: swimming helps to achieve self-control of movements and also stimulates their circulation, providing them a greater autonomy. Another example would be indoor football, this one improves not only physical skills it also improves a social development.

Parents must know that there are risks for their children too, this risks cause by an anomaly in their bodies, this risks are not for all the persons who suffer from Down syndrome, this risks are only present in a certain amount of persons who have DS

Expert's studies demonstrated that:

10-40% of children with Down's syndrome have atlantoaxial instability. These children might run the risk of spinal cord compression if they play sport. The aim of our study was to assess this presumed risk. We obtained 282 radiographs of the cervical spine. The atlantoaxial distance was more than 4 mm in 91 children.

(The Lancet volume 342, issue 8870, 1993, p. 511)

So knowing this, parents should prevent future damage in their children and they should look for better healthy alternatives for their physical development

There exists contact and non-contact sports, for example boxing it's a contact sport, but swimming it is not. Why is this important to know? Because contact sports involve collision and that it is not too good for a person with Down syndrome.

How an article says and recommends:

Contact sports involve collision (boxing, football, wrestling) or impact (basketball, diving, gymnastics). Noncontact sports are strenuous (aerobics, crew, swimming), moderately strenuous (badminton, table tennis), or nonstrenuous (archery, golf, riflery). A child's disability plays a significant role in decision making, but specific guidelines are few. It would seem that, in

general, children with disabilities, including Down syndrome, should avoid collision sports.

(Orthop Clin N Am 34, 2003, p. 439)

In conclusion, doing sport it's good for all kind of people, it's a healthy way to improve the physical and social development in many cases for persons with DS. Parents should consider many things and help their children to guide them to a better type of life and make them to feel that they care. Finally, person with DS are capable to develop skills like anyone else, it will only take time and patient to do it.

Chapter IV

Down syndrome treatment

4. Treatment

Now it is the introduction to the treatment part. This part it's the most important one cause' it talks about the real treatment that they usually receive and the treatment that they should receive from part of the society. This part conforms the medical part too, that it's a responsibility from the parents or the closer familiars, all this for the good of the Down syndrome community.

This topic exists because in this world there it is so much ignorance about the people with genetic conditions. The ignorance makes people think that this type of persons are ultra retarded or are sick people, in conclusion the think that the Down syndrome or another genetic anomalies are a disease, but how this work emphasize they are not. So for this ignorance it comes the bad treatments to this type of persons and this people needs to come out of that bubble of ignorance with advices, having talks about the treatments that they deserve and reading information. All this with the objective of improve a better society and community.

4.1 Social treatment.

The persons with Down syndrome love to interact with others, and they usually do it in a kind and friendly way because their minds thinks in a different way but they understand the message that people are trying to say to them, they are not stupid, they only have a slower

development and response. People should try to talk to them in a normal way like they are talking with a friend and not being afraid, cause' there it comes the confusion to the minds of the persons with Down syndrome, they know that you are thinking something bad of them and they will start to feel like an awkward person in an awkward moment with a person who doesn't know how to talk properly to them.

The social treatment, as it name says it, conforms the social part, but it is not talking only from people who doesn't know them, it is talking about the closer ones; the parents and familiars. There are different actions that the both sites should take for a better social treatment.

4.1.1. From family.

The family is the most important thing in the life for most of the people. The Down syndrome community is not an exception. The actions from the family are different than from other people, because the family plays a supporting role where they constantly should being supporting their familiar with Down syndrome. The family is the one who talks with the familiar with DS about the problems that are in his mind and how to solve them in the best

way possible, all this for looking the wellness of the person with DS. The family is the one who gives all the love to them too; the persons with Down syndrome are always looking the feeling of love in their circles.

The family is affected before and after the born of the child with Ds, as this study says:

The results indicate that each person crosses the feelings before the situation of the disability. The coping process seems to have an impact on the care and attention actions, and all the members of the family. The expectations of the future revolve around the welfare and autonomy of the child. Therefore, the characteristics of the family dynamics cited are linked.

(*Eureka* [online]. 2012, vol.9, n.1, p. 69-77)

4.1.2. From other people.

Now talking about the treatment from other people, it is different from the family in the part of responsibilities because other people don't know how that person with Down syndrome is and how is his life, the thing that other people should do when a person with Down syndrome wants to talk with them is react in a good and quite way, people need to remember that they are normal people like us and they can understand when people don't want their presence, all this for not knowing how a person with DS really is.

If people want to find a solution, they should make training courses about how to establish a better community and society between a person without genetic problems and a person with

DS or other genetic problems. These training courses should be an obligation in many public and private sectors. Another individual solution would be that people start to read articles from the internet related to the social treatment and the life of a person with Down syndrome.

Talking about negative reactions to them, people with Down syndrome knows when you are feeling uncomfortable with them, as a study declares:

The adolescent with Down syndrome, currently with a mental age of 7-8 years, understands very well how is valued or rejected, suffers the permanent stress of real discrimination, knows that society is trying to avoid by all means that more people born as them. And it is at that time of life -adolescence- when their systems of values , about themselves and about others, outline.

(Attitudes and mentalities of society in the face of Down syndrome, 2012, p.69)

4.2 Medical treatment.

The medical part is important too, because Down syndrome is not a disease but it produces them. The more common diseases are related to hearth problems and there it is when the family participates because they have the responsibility of take care with the familiar and hope the best for his life. The family wants the less pain possible for their familiar with DS so they should go to visit the specialist of anomalies, as Down syndrome, in all the phases of the life of the patient for following a medical history.

There are studies about the heart defects as this study says:

Down syndrome is the most frequently chromosomal anomaly. In this syndrome, heart defects are frequent, affecting between 35-60% of the

patients. The most common anomaly is the atrioventricular canal complete, which is almost exclusive to these patients, that they represent up to 80% of all cases diagnosed. Other anomalies that may arise are communication atrial septal defect, ventricular septal defect, patent ductus arteriosus and tetralogy of Fallot.

(Congenital heart diseases in children with Down syndrome, 2012, p. 415)

The medical part can vary on the person, not all of the people with DS have the same diseases or suffer the same diseases in the course of their life, and each one reacts in a different way to these diseases. So there it is when the family should find different specialists for specific situations that the person with Down syndrome is going through.

If the family is not present in the life of the child with Down syndrome or they don't even care, the child will develop in a bad and probably in a painful way if he or she is not receiving medical treatment of any type, and there it is when other kind of people interfere in the situation.

A cause of delay in the acquisition of motor milestones can be the medical problems that are usually associated with the syndrome, such as cardiac, gastric, intestinal problems, upper respiratory tract infections and ear canal infections. So there it is when the family should go to visit a specialist.

As an investigation says:

People with DS frequently have alterations in the structures of their locomotor system due to an association of muscular hypotonia and ligamentous laxity,

more or less pronounced. The joint instability is increased, since the function of containing the soft tissues of the joints is diminished, and this causes that the joints subjected to a more continuous load or to a great mobility, have a greater affectation.

(International Medicine Magazine about Down syndrome, 2006, p. 18-24)

Conclusions

At the end of this monographic work it is concluded that:

- Down syndrome is not a disease; it is simply a genetic condition that generates diseases throughout the life of those who suffer from it.
- We deal with different issues first to get to the problem that is the treatment that these people receive, both social and medical and all this to make clear the subject we are dealing with and the people who involve it.
- When we talk about diseases we can make it clear that the most common diseases are the ones that are related to hearth problems.
- When we talk about mental problems we should know that these people, sometimes, suffer from depression caused by thoughts that have been generated by other people that make them feel in a bad way or underrated. Then other mental problems could appear but it is different in each person and they are not very common.

- The most characteristic part of this type of people is their physique; the shape of their faces is remarkable and can be easily related to Down syndrome. Now, if we talk about the thoughts that other people have when they look at them, not all the people of course only the uninformed people, would be that they are retarded or that they can't understand you and you have to talk in a weird way. This is obviously wrong and the fact of thinking it is why this work exists, for advice and inform how to treat them in the best possible way.
- If we want to talk to a person with Down syndrome, we shouldn't be afraid cause' they are the most adorable and happy persons right now in the earth and we should follow the way that they see the world. But if they feel that you are not comfortable with them, they will probably start to feel like a weird person and they will be confused as well; when it comes to the depression cause' by the contempt from other people.
- People should start to be more informed about the social and medical treatment that they need, and apply all this advice for living in a better sustainable society.

Recommendations

At the end of this work it is recommended that:

1. All the persons should know about what to do when they are in a position where they have to interact with a person with Down syndrome, and for doing this they should take the advice of experts by going to conferences or reading information on the Internet. This kind of things would make a change in our society and them probably will make a difference.
2. People who have familiars with Down syndrome, should support them in their life and make them feel appreciated and important to the family, cause' they are disabled people who obviously need some help and they need to feel good to go on in their life goals.
3. If you see a person that reacts in a bad way when they see a disabled person, stop them an advise them how to treat them in a way where the person with DS doesn't feel awkward and disrespected or simply send him a link where he can find a lot of information about how to treat and react to them.

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