

An Analytical Study on Influence of Family Environment on the Development of Person Suffering from Down's Syndrome

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ABSTRACT

“You’re not disabled by the disabilities you have, you are able by the ability you have.” Down’s syndrome also known as Trisomy21, is a genetic disorder caused by the presence of a third copy of chromosome. It is typically associated with physical growth delays, idiosyncratic facial features and mild to moderate intellectual growth. It is a highly common yet oblivious arena for awareness in India due to stigmatization and lack of understanding pertaining to this phenomenon. This study aims at investigating the family environment of a child suffering with Down’s syndrome and care towards a child can promote holistic development of a child. Timely intervention and sentience of Down’s syndrome can burgeon the mental growth of a child enduring Down’s syndrome. The author has taken up a specific study and has focused on the development of a child; Rashi Vyas in order to substantiate the normative study opted by her. As quoted above it is a matter of approach which can change the outcome and so can be seen by analyzing the family environment of Ms. Rashi Vyas.

Key words: *Down’s syndrome, Trisomy21, Family Environment*

Down’s syndrome also known as *Trisomy21*, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is typically associated with physical

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growth delays, characteristic facial features and mild to moderate intellectual disability. The average IQ of a young adult with Down's syndrome is 50, equivalent to the mental ability of an 8- or 9-year-old child, but this can vary widely. The parents of the affected individual are typically genetically normal (*Chan & Iacono, 2001*). The extra chromosome occurs by chance. The possibility increases from less than 0.1% in 20-year-old mothers to 3% in that age 45. As seen in people with development disabilities, Down's syndrome is the most common disability in the world. Down's syndrome is a genetic condition in which a person has 47 chromosomes instead of the usual 46 (*Reddy, Williams & Vaughan, 2002*). The estimate incidence of Down's syndrome in the world is 1:1000 to 1:1100 live births, where in India is a developing country and incidence of Down's Syndrome is 1:800(which means approximately 32,000 babies with Down's Syndrome as born per year). There is no known behavioral activity or environmental factor that changes the possibility (*Roizen & Patterson, 2003*). It can be identified during pregnancy by prenatal screening followed by diagnostic testing or after birth by direct observation and genetic testing. Since the introduction of screening, pregnancies with the diagnosis are often terminated. Regular screening for health problems common in Down's syndrome is recommended throughout the person's life (*Kliegma, 2011*).

There is no cure for it but education and proper care have been shown to improve quality of life. Some children with Down's syndrome are educated in typical school classes, while others require more specialized education. Some individuals with this problem graduate from high school and a few attend post-secondary education (*Smith, 2001*). Life expectancy is around 50 to 60 years in the develop world with proper health care.

It is one of the most common chromosome abnormalities in humans which occur in about one per 1000 babies born each year. In 2013, Down's syndrome was present in 8.5 million individuals and resulted in 36,000 deaths down from 43,000 deaths in 1990. It is named after John Langdon Down, the British doctor who fully described the syndrome in 1866.

Guidelines recommend screening for Down's syndrome to be offered to all pregnant women, regardless of age. A number of tests are used, with varying levels of accuracy. They are typically used in combination to increase the detection rate. None can be definitive, thus if screening is positive, either amniocentesis or chorionic villous sampling is required to confirm the diagnosis. Screening in both the first and second trimesters is better than just screening in the first trimester. The different screening techniques in use are able to pick up 90 to 95% of cases with a false-positive rate of 2 to 5%.

Problem:

This study aims at investigating the family environment of a child suffering with Down's syndrome as presence of a positive family environment and care towards a child can improve quality of life because the family is profoundly important to the developmental, emotional and cognitive growth of a child. (*Gold, 2013*)

Methodology:

This investigation is a case study that involves only observation. During the study, Rashi was observed for 1hr, 30min for 1 year 6 months because other Down's syndrome children were observed so it's an opportunity to compare the pattern of behaviour.

Sample:

Ms. Rashi Vyas, an eighteen year old girl with Down's syndrome, who is currently a resident in Jodhpur (Raj) with her family.

Rashi's mother is a house-wife and father is self employed. She has two elder sisters. She was diagnosed when 3 year old (2001) but Down's syndrome is just not a mental disability it has several physical problems which were hypothyroid, heart disease, diabetes and sleep apnea. Rashi does not have academic background but family support and early interventions are leading to live a good life. It has been observed that she is very interactive with family member and other people.

Key points:

- To observe a family environment, therefore regular interaction with subject and subject's family is necessary.
- Allowing Down's syndrome persons to be interactive and participate in daily activities for their well being.
- Positive family Environment with clear and constant communication play crucial role in establishing improved quality of life among Down's syndrome.
- Family Environment should be taken into consideration when assessing the development of Down's syndrome child.

DISCUSSION:

In this study, affect of family environment on Rashi has been observed where she is getting affection, values and manners. The thought of their family for Rashi is "they never show her that she is a special child, they are treating her as NORMAL." Her mother keeps herself updated about the physical changes and regularly follows the check-up. Rashi can read, write and operate simple mathematical operation. She is gadget friendly so she likes to interact with people on social media. Though she does not have academic background but she can look after her bodily needs and hygiene. She has good emotional intelligence. With time, she has learnt to control her emotions rather than blasting them out. She loves music and dance and she is learning dance for developing skills. She had done various stage performances.

LIMITATIONS:

It is important to be cautious in generalizing the findings of this case study, one should keep in mind that all findings are based on a single subject, who is not representative of the population of teenage with Down's syndrome in general. Furthermore, individual differences can affect results of study.

CONCLUSION:

It is believed that a positive family environment, awareness and early intervention greatly improve the quality of life and development of Down's syndrome child. A family support and positive attitude with Down's syndrome child increase their involvement in daily activities, social bonding and capabilities because it is believed that "School Counts, but home is more lasting over the year."

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