

## **A Study on Adjustment Level of Siblings of Individual with Down Syndrome**

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### **ABSTRACT**

**Introduction:** Adjustment could be defined as a process by which a living organism acquires a particular way of acting or behavior or action. There are two type of adjustment. Human behavior seeks to adjustment to external conditions and adjustment to internal conditions. As a person grows older, adjustment to external conditions assumes more and more importance compared to adjustment to internal conditions. So this research will be an attempt on this path.

**Aim:** To identify the level of adjustment of siblings of individuals with Down syndrome.

**Methodology:** 30 siblings of individual with Down syndrome were selected through accidental sampling method from Shri Kailash Disability & Rehabilitation Centre, Azamgarh, U.P. Bell Adjustment Inventory (Indian Adoption) by Dr R. K. Ojha was used to obtain the score on adjustment.

**Result:** result indicates that the siblings of Down syndrome individuals are found average adjustment in all domains of adjustment except health.

**Conclusion:** It concluded that siblings of individual with Down syndrome are more prone to develop health related issues.

**Keywords:** Adjustment, Down Syndrome, Siblings, Health Adjustment,

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### **I. INTRODUCTION**

Adjustment in life is very crucial. It is because the one who fails to adjust in life invites- 1. Mental stress which paves way for- 2. Decline in health 3. Worse work efficiency and 4. Sometimes even exclusion from society (because the one who cannot control his desires and needs becomes greedy and can commit any crime such as robbery or even murder to fulfill his needs). The term adjustment refers to the behavioral process of balancing our needs (Conflict induced), or needs against obstacles in the environment. Humans and animals regularly do this. Adjustment as a process describes and explains the way and means of individual's adaptation to self and environment. A sequence of adjustment begins when a need is felt and ends when it is satisfied. It is "The process of finding and adopting modes of behaviour suitable to the environment of the change in the environment." [1<sup>a</sup>]

In general, the adjustment process involves four parts:

1. A need or motive in the form of a strong persistent stimulus
2. The thwarting or non fulfillment of this need
3. Varied activity, or exploratory behaviour accompanied by problem solving
4. Some response that removes or at least reduces the initiating stimulus and completes the adjustment.

Social and cultural adjustments are similar to physiological adjustments. People strive to be comfortable in their surroundings and to have their psychological needs (such as love or affirmation) met through the social networks they inhabit. When needs arise, especially in new or changed surroundings. They impel interpersonal activity meant to satisfy those needs. In this way, people increase their familiarity and comfort with their environments, and they come to expect that their needs will be met in the future through their social networks. Ongoing difficulties in social and cultural adjustment may be accompanied by anxiety and depression. While you are growing, this is very difficult to live with a person with permanent mental disability in home, especially with your sibling, who has Down syndrome. When you are growing with such type of individual, you have to plan not only your present but future also, it may cause of stress in your life because after parent, you have to take care of your sibling. That's why, it is stated that Mental Disability hampers the process of adjustment.

Down syndrome is one of the types of mental disability due to abnormalities in chromosome in humans [2]. It occurs in about one per 1000 babies born each year [3]. Down syndrome, also known as trisomy 21, 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 growth delays, characteristic facial features and mild to moderate intellectual disability. The average IQ of a young adult with Down 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 [4]. The extra chromosome occurs by chance [5<sup>a</sup>]. The possibility increases from less than 0.1% in 20-year-old mothers to 3% in those age 45 [6]. There is no known behavioral activity or environmental factor that changes the possibility [5<sup>b</sup>]. There are three types of chromosomal aberrations in Down's syndrome:

1. TRISOMY-21 is the commonest where karyotype of mother is normal.
2. MOSAICISM, with both normal and trisomic cells present.
3. TRANSLOCATION between chromosome 21 and 15. Thus, the total number of chromosomes is 46, in spite of 3 chromosomes at 21. The translocation is inherited, with asymptomatic carriers containing only 45 chromosomes.

There is no cure for Down syndrome [7]. Education and proper care have been shown to improve quality of life [8]. When the diagnosis of Down syndrome is made questions are often asked about the effects of this on the family and particularly the other children in the family.

In the past it was assumed that the effects of having a child with Down syndrome in the family were negative. Since the 1970's and 1980's children are more likely to be brought up in the family home and attend mainstream education. In an Irish study Egan (2000) identified that 95% of all Irish children with Down syndrome had at least one sibling and the most commonly occurring number of children in the family was three. She suggested that further investigation may provide important insights into the role brothers and sisters play in each other's lives [9]. Since the 1990's there has been increased focus on the experience of siblings as well as parents. The sibling relationship is a complex one regardless of the presence of Down syndrome. Meyer and Vadasy (2000) found that just like their parents, children need information about the disability in order to alleviate worries that they didn't cause it or they might catch it [10]. Porter and McKenzie (2000) agree with other writers about the need of siblings for information. They suggest that siblings experience similar negative feelings as their parents. Talking about their feelings and negative emotions and resentment helps siblings achieve a greater understanding. It can also give them skills to help them deal with conflicts that may arise because of their sibling's disability. They can receive permission to pursue their own growth and have their needs met. The sibling relationship can grow stronger when they accept their negative feelings and have the capability to be the most enduring of all relationships. In any family sibling relationships are complex with mixed emotions but they have the potential to influence positively the lives of siblings with and without disability [11]. But the question is arise that the individual with down syndrome have good impact on their quality of life as well as adjustment but what is the impact of down syndrome on their sibling's Adjustment. How is it influence their Home, Health, Social and Emotional adjustment. Present study is the attempt to identify the level of adjustment in siblings of Down syndrome individual.

## **II. AIM**

To identify the level of adjustment of siblings of individual with Down syndrome.

### **Hypothesis of The Study**

1. There will be satisfactory adjustment of siblings of individual with Down's syndrome.
  - 1.01 There will be satisfactory adjustment as home adjustment of siblings of individual with Down's syndrome.
  - 1.02 There will be satisfactory adjustment as health adjustment of siblings of individual with Down's syndrome.
  - 1.03 There will be satisfactory adjustment as social adjustment of siblings of individual with Down's syndrome.
  - 1.04 There will be satisfactory adjustment as emotional adjustment of siblings of individual with Down's syndrome.

## **III. METHODOLOGY**

A sample of 30 siblings of Down syndrome (of both sexes) was covered by convenient sampling method from Shri Kailash Disability & Rehabilitation Centre, Azamgarh through accidental sampling. The sample was selected on the basis of age range between 10 years to 25 years.

**Table I:** Details of Sample Distribution

Variables	Group	No. of Siblings (N=30)	Percentage
SEX	Male	14	46.7
	Female	16	53.3
AGE	10 Years to 15 Years	16	53.3
	16 Years to 25 Years	14	46.7

#### IV. INSTRUMENT

##### Bell Adjustment inventory [1<sup>b</sup>]

Bell's Adjustment inventory (Student Form) by Dr. R.K. Ojha in 2006, which is an Indian adaptation of the Bell's Adjustment Inventory, was used to obtain the score on adjustment of the participants. There are 140 items in relation to four domain of adjustment i.e. Home, Health, Social and Emotional in the inventory. Every domain have equal no of item i.e. 35. The responses based on two points scaling i.e. Yes and No. For every Yes participant will get one mark and zero on No response. High score on the inventory signify poor adjustment and low score batter adjustment in different specific areas and also in respect of adjustment taken as a whole. The test was found highly reliable by computing split half and test retest method of reliability which was found 0.84,0.81,0.87,0.89 by split-half method,0.91,0.90,0.89,0.92 by test retest method respectively Home Adjustment, Health Adjustment, Social Adjustment, Emotional Adjustment .The validity coefficient (correlation between Kumar, K. Adjustment inventory and Bell adjustment inventory) of the inventory for home, health, social and emotional areas was 0.72, 0.79, 0.82 and 0.81 respectively.

#### V. PROCEDURE FOR DATA COLLECTION

The inventory was administered on a one to one basis. First rapport was established between the test administrator and the test-giver. Following which the subject was informed that the test to be taken was a simple one. The following instructions were given to the sample: "This inventory consists of four parts. 35 statements are given in each part. Alternatives "Yes" and "No" are given against each statement. If you wish to mark the statement in "Yes" i.e. you agree with the facts given in the statement put a cross in the box given below "Yes". If your answer is negative i.e. not agree with the facts given in the statement then put across in the given below "No". Though there is no time limit, still try to answer all questions quickly. After completing, the researcher collected the scale from examinee and thanked for their participation.

#### VI. RESULTS

According to manual, scoring was done and data interpreted statistically, which has presented in tabular form. As per our hypothesis-

Hypothesis 01: There will be satisfactory adjustment of siblings of individual with Down's syndrome, according to our result this can be stated that our hypothesis is not rejected. As -

1.01 There will be satisfactory adjustment as home adjustment of siblings of individual with Down's syndrome.

Level of Home Adjustment		
Levels	No. of Siblings (N=30)	%
Excellent	1	3.3
Good	3	10
Average	19	63.3
Unsatisfactory	5	16.7
Very unsatisfactory	2	6.7

**Table-01**

Table -01 show that 76.6 % of participants have fallen on above average i.e. Average followed by Good to Excellent level of adjustment as home adjustment, hence our hypothesis is not rejected.

1.02 There will be excellent adjustment as health adjustment of siblings of individual with Down's syndrome.

Level of Health Adjustment		
Levels	No. of Siblings (N=30)	%
Excellent	2	6.6
Good	3	10
Average	8	26.7
Unsatisfactory	6	20
Very unsatisfactory	11	36.7

**Table-02**

Table -02 show that 56.7 % of participants have fallen in below average level of adjustment under this domain i.e. unsatisfactory followed by very unsatisfactory level of adjustment as Health Adjustment, hence our hypothesis is rejected.

1.03 There will be excellent adjustment as social adjustment of siblings of individual with Down's syndrome.

Level of Social Adjustment		
Levels	No. of Siblings (N=30)	%
Good	3	10
Average	17	56.7
Unsatisfactory	4	13.3
Very unsatisfactory	6	20

Table-03

Table -03 show that 66.7 % of participants have fallen in above average level of adjustment under this domain i.e. average followed by good level of adjustment as Social Adjustment, hence our hypothesis is not rejected.

1.04 There will be excellent adjustment as emotional adjustment of siblings of individual with Down's syndrome

Level of Emotional Adjustment		
Levels	No. of Siblings (N=30)	%
Good	1	3.3
Average	15	50
Unsatisfactory	2	6.7
Very unsatisfactory	12	40

Table-04

Table -04 show that 53.3 % of participants have fallen in above average level followed by Good adjustment under this domain i.e. average followed by good level of adjustment as Emotional Adjustment, hence our hypothesis is not rejected.

Overall results indicate that the **siblings of individual with Down syndrome have satisfactory adjustment in all domain of test except health adjustment.**

## VII. DISCUSSION AND INTERPRETATION

Families of children with special needs are often exposed to a variety of beneficial and difficult experiences. Possible positive impacts of such experiences include increased awareness and acceptance of persons with special characteristics, heightened academic performance, and altruism. On the other hand, extra stressors and variables within the family, including added responsibilities, decreased parental attention, and the child's behavioural problems, may affect each member more negatively. These experiences may result in a constellation of unique life changes coping mechanisms and attitude responses for tall family members, including typically developing siblings. In our study we found that siblings show satisfactory adjustment in Home, Social and Emotional dimension of scale but their health adjustment was unsatisfactory.

All the siblings of Down syndrome were asked regarding their home adjustment. The table-01 indicates the levels of adjustment as on one hand 63.3 percent of siblings had average home adjustment on the other hand 16.7 percent of siblings had unsatisfactory home adjustment. Although 10 percent of siblings had good home adjustment yet one can see from the table the level of home adjustment for 6.7 percent of siblings was very unsatisfactory. However, there were only 3.3 percent of siblings whose level of home adjustment was excellent. Home adjustment is based on cohesiveness between the family members, as result of present research indicates that home adjustment found above satisfactory of siblings with Down syndrome because of their cohesiveness between the relationships. It has been found that siblings of young children with Down syndrome spend adequate time with and have a close relationship with their brother or sister [12, 13], which makes their strong bonding between the family members [14]. Siblings of adults with Down syndrome reported significantly proper contact and positive affect in the relationship with the brother or sister [15<sup>a</sup>] such type of interaction makes home adjustment better and smoother. However, who found unsatisfactory home adjustment in the study, those participants interviewed for exploring the causes behind that. Dysfunctional family environment was responsible for that and these participants were found satisfactory adjustment with social and emotional adjustment.

The table-02 shows the health adjustment level. 36.7 percent of siblings of Down syndrome had very unsatisfactory level of health adjustment. 26.7 percent of siblings of Down syndrome had average level of health adjustment. The health adjustment level of 20 percent of siblings was unsatisfactory. While health adjustment level for 10 percent of siblings of Down syndrome were good followed by 6.6 percent were excellent. Under this domain of adjustment this is very clear that 56.7 % of participants show unsatisfactory adjustment with Health, which was the serious issue for families.

Present finding indicates probability of chronic diseases in siblings of individual with Down syndrome, which can hamper physical as well as mental health. The cause behind that is stubborn and attention seeking behaviour of such type individual. Person with Down syndrome has limited expressed emotions due to low level of IQ, which made them stubborn and aggressive toward their demands, they usually adopt attention seeking behaviour also which can lead excessive stress , anxiety and depression in their life. Poor level of stress management and its induce problems (pain of any kind, sleep problems, autoimmune diseases, digestive problems, skin conditions such as eczema, heart disease, reproductive issues, memory problems etc) makes critical changes in their life in the form of diseases. The level of social adjustment was also identified with the help of the scale, in present study. This is clear from table-03 that the social adjustment level for more than half (56.7 %) of the siblings of Down syndrome were found average. Further, table describes that 20 percents of siblings of Down syndrome had very unsatisfactory level of social adjustment followed by 13.3 percent were unsatisfactory. However, the level of social adjustment for 10 percent of siblings of Down syndrome was found good. Researches indicate that Siblings may not only become responsible, caring and emotionally closed when their parents are involved in maintaining the relationships among brothers and sisters but also shows greater positive affect in the sibling relationship which was found with lower educational level and greater use of problem-focused coping by the non-disabled sibling. Further, more shared activities were reported when the brother or sister with the disability had higher levels of independence, and more sibling contact was reported when the siblings lived closer together. The higher levels of positive affect and engagement in shared activities were found. Resources and appraisals were also an important factor found for siblings of adults with Down syndrome [15<sup>b</sup>].in clinical interview we found that phenomena of sharing and understanding of others need, improve social adjustment of siblings of individuals with Down syndrome. Those were assessed very unsatisfactory adjustment, they expressed problem in sharing and poor performance in social activity due to their nature of personality. As shown in table-04 that the level of emotional adjustment for half (50 %) of the siblings of Down syndrome was average followed by 3.3 % good adjustment yet it is very unsatisfactory for 40 percent of siblings of Down syndrome followed by 6.7% unsatisfactory in present research. Which indicate problems perceived on emotional adjustment of the siblings of individual with Down syndrome because the relationship between siblings is considered to be one of the most enduring relationships within families. There is trends for siblings with a brother or sister with Down syndrome to be more likely to report that their thoughts about having children and their plans for the future had been affected. There are a number of studies that have examined the impact on siblings of having a brother or sister with Down syndrome, although these generally focus on children who are in middle childhood or older. These studies typically focus on behavior or other adjustment problems in the sibling and/or on the relationship between the typically developing child and the child with Down syndrome. It has been found that sisters often grow up with the expectation that they will take on additional care giving and household responsibilities for their sibling in the future [16,17,18]. Moreover, women in general tend to use more emotion focused coping strategies than men [19]. while there were some initial reports of adjustment difficulty [20] but recent researchers found that the siblings have favorable self-concepts [21] and that many believe they have developed additional strengths at emotional level for their adjustment because of their sibling with Down syndrome [22,23]. There are no important differences in the adjustment of the siblings of a child with Down syndrome and children in families where all are developing typically [24, 25]. It was found that siblings of children with Down syndrome not only similar on many measures, but also showed somewhat more positive relationships with their siblings [26, 27]. Good sibling relationships are often perceived by mothers as evidence of good parenting[28]. Although very little understanding of how parents accomplish this task yet it is clear that the majority do so[29] Orsmond & Seltzer (2006) siblings of adults with Down syndrome displayed greater amounts of interpersonal contact with their brother/sister with disabilities, as well as more positive effect, and lesser amounts of pessimism were found [30,31].In studies of health and Alzheimer's disease the age of 45 years is often considered the first of the 'older-age' periods for persons with Down syndrome [32<sup>a</sup>].Lower levels of behaviour problems and closer sibling relationships for siblings in the Down syndrome may more relate to their brother/ sister's personality and generally. Conversely, having fewer persons who lost services would seem more related to higher levels of parent education and higher socio-economic status levels often found in groups with Down syndrome versus with other disabilities [33, 34]. Age group differences in sibling relationships quality are particularly interesting with increased life expectancies among adults with Down syndrome [35].Many persons with the syndrome who lived into their fifties, sixties and seventies with parents who may be 30–40 years older, these adult siblings therefore constitute a first generation of likely caregivers. Many of these surviving adults with Down syndrome will themselves have health problems

[32<sup>b</sup>]. It was found that spending time with one's brother/sister with Down syndrome is better [36]. Although greater sociability and fewer behaviour problems have been thought to contribute to the Down syndrome advantage during the childhood years [37], such findings have not yet been noted during adulthood. If taken together in theoretical and practical implications lesser amounts of maladaptive behaviour [38], greater amounts of looking and smiling to others [39,40] and being perceived as having a more sociable personality all may be operating [41]. There are a number of things, which leads our adjustment in life but if a person is going to live with an individual of Down syndrome, person will perform his adjustment as per his perception and level of stress. Present research revealed that sibling shows satisfactory level of adjustment on different criteria of adjustment but health adjustment was a topic for further research.

## VIII. CONCLUSION

It is concluded that siblings of individual with Down syndrome showed more positive social and emotional attitude. They expressed a more positive representation of their brothers or sisters' life as well as their own. The representation of their brothers or sisters' future seems to be characterized by a perceived reduction but their health adjustment was found unsatisfactory, which can hamper physical and mental health of the siblings.

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