

A Study of Down syndrome - The Medicare & Positive Parenting for A Healthy India

* Krishnekumaar

** Dr. K.S. Meenakshisundaram

* PhD Research Scholar “Sri Chandrasekarendra Saraswathi Viswa Maha Vidyalaya”
SCSVMV University, Enathur

** Professor & Director & Head, Centralized Academic Administration at Great Lakes
Institute of Management, Manamai, Chennai, and Tamilnadu

Abstract:

Down syndrome (or Down's syndrome) is the chromosomal disorder, which is caused by an error in cell division that results in an extra 21st chromosome and which is associated with some impairment of cognitive disability, physical growth and appearance. It can be prevented before the birth of a baby by a positive attitude coupled with proper education to the pregnant women, which were done in the western countries. It is not a curable disease but the positive attitude of parents will reduce the stress and will also develop the ability to effectively communicate which will influence the wellbeing of the respective family. Further, timely adequate medical attention and care will help for a healthy atmosphere, which will result, to the increase the life span of the affected. India reported to have 13, 31,338 and China has 16, 23,559 citizens with Down syndrome when compared to 4, 00,000 in United States as per 2014 statistics. There is no separate legislation in India for Down syndrome and the financial support is not adequate for such affected children. Hence, in this paper, an attempt has been made to throw light on the various aspects of Down syndrome, the measures taken in various countries and the support provided. A comparison of the life of Down syndrome prevailing in India, United States and China has been made. The results of a SWOT analysis made with reference to Down syndrome families will be useful. The suggestion of Health Insurance coverage to the Down syndrome will be of very much use to the affected ones and to the affected family members.

Keywords: Patient Protection and Affordable Care Act (**PPACA**), Preconception and Prenatal Diagnostic Techniques (**PCPNDT**) Rules, Chronic Villus Sampling (**CVs**), Peruntaneous Umbilical Blood Sampling (**PUBS**), Vineland Adaptive Behaviour Scales (**VABS**).

Introduction:

What is Down syndrome?

In General, the babies with Down syndrome have an extra chromosome in each cell, which can affect all parts of the Body. According to Dr D K Chopade, Geneticist and Founder President of Down syndrome Care Association has stated that there is no awareness of Down syndrome in general society as well as in Doctors society too. Further, his analysis revealed that Down syndrome is most commonly occurring Chromosomal disorders in newborn, which has incidence of 1 in 800 children. Down syndrome is a chromosomal disorder caused by an error in cell division that results in an extra 21st chromosome. Down syndrome is associated with some impairment of cognitive disability, physical growth and appearance. Most individuals with Down syndrome have intellectual disability, which has an IQ (Intelligence Quotient) of 50-70 whereas the moderate rang IQ of 35-30.

Common symptoms of Down syndrome:

- a. Problems with loose muscles, joints, bones and movement
- b. Vision and hearing difficulties like eyes that slant, a small mouth and small ears
- c. Vulnerability of infection
- d. Problem with digestion

- e.** Lung Disorders
- f.** Heart Defects
- g.** Single crease across the palms
- h.** Head shape flatter at the back
- i.** Small nose with flat nasal bridge
- j.** Lower than Birth average weight
- k.** Short stock body shape

People with Down syndrome have high risk of getting leukemia and other blood disorders. They do their walking, using toilet, talking, reading and writing at their own pace.



In China the research studies reveals that Down syndrome is characterized by congenital malfunctions especially of heart and gastrointestinal tract, which result in high mortality rate. Cognitive Skills grow at faster rate for Down syndrome rather than normally developing children. Down syndrome children with moderate and severe levels of cognitive disability were reunited at Children's Health Care Outpatient Clinic of Children's hospital (Zhejiang University, School of Medicine).

Why Babies are born with Down syndrome?

The Child inherits extra genetic material from the parents causes Down syndrome. Older women, when they conceive, have chances of having Baby with Down syndrome. Some families have genetic profiles prone to Down syndrome while others have random event. We cannot blame oneself for Down syndrome as we have not caused anything extra resulting in child born with Down syndrome.



How to Overcome the Challenges of Down syndrome?

According to Dr Rekha Ramachandran, Co-founder and Chairperson of Down syndrome Federation of India and she introduced Nutritional Metabolic Therapy for people with Down syndrome. She has made numerous researches and is successful in meeting the challenges of medicare and positive parenting towards her own Down syndrome child.

There is no cure for Down syndrome, but there are solutions for a reasonably good quality of Life, which are as under:-

- a. Early intervention strategies
- b. Proper Support System
- c. Suitable education
- d. Public Awareness
- e. Parent's education for handling Down syndrome Children

f. Laws Applicable for Disabled is available for Down syndrome also, but there is no Special Legislation in India viz., Disabilities Act, 1995.

We need the following to overcome Down syndrome:-

1. Unconditional Love towards the Child
2. Way in which family value the child
3. Advocating for children's needs shows results of strength.
4. Unavailability of Special Staff
5. Inadequate Care Providers
6. Mismatching of Syllabus for Down syndrome
7. Inadequate requisite facilities
8. No proper education even in existing Down syndrome Special Schools



A SWOT Analysis of Down Syndrome Families

Strength:

Research on Young Adults with Down syndrome and have ageing parents was conducted in United States. Strength factors which increases resilience and weakness factors vulnerability. The study reveals that increasing families caring for individuals with Down syndrome. Further, the findings of their study are as under:-

- a. Normally the majority of families live ordinary life with Children having Down syndrome.
- b. Does not have additional demands and challenges to cope with
- c. Resources are procured to meet the Additional needs of Down syndrome Child or Adult to live happy and ordinary life
- d. No more marriage breakdown than in rest of population
- e. There are no extra demands of siblings in the family
- f. Less stress in case of Down syndrome child families rather than similar levels of Intellectual disabilities
- g. Evidence of ageing of parents who have adults with Down syndrome still live at home has physical life satisfaction.

Increasing number of Chinese women choose caesarean as less painful delivery and hence one per family is the size of family due to family planning. In Urban areas of china, most families have one-child nuclear families except those who have a Down syndrome child. Whereas in rural areas couples are permitted to have second child especially if first is female. Grand Parents live with Down syndrome children and such children are focus of the family.

Weaknesses:

1. Poor Marital relationships and Disharmony in family
2. Poverty, poor housing and employment
3. Low Self esteem and self confidence

4. Brothers and sisters show behavioural difficulties
5. Parents more likely to cope-up, but experiencing depression or health problems
6. Family relations affected and strained
7. Hard times parents need information, extended family services to pinpoint to improve
8. Members of family broke out when they lack support for Down syndrome
9. Passive and ineffective coping strategies
10. Emotional ambivalence towards the child

Opportunities:

- Create opportunities for suitable education
- Acceptable environment
- Awareness about condition of society
- Special Skill training based on individual capabilities
- Creating specific job profiles for individuals.

Threats:

- Down syndrome is a genetic disease
- Down syndrome children needs Support System
- Parents of Down syndrome children experience guilt and anger
- Indifference towards the child, hatred, inferiority complex and a lot of suffering
- Clinical ignorance about the conditions of the patient
- Not properly attended at Schools, Colleges, Hospitals and workplace
- Not getting proper educational support
- Discrimination and hardly get their share of public recognition
- Concerns like social acceptance, behavioural problems, and financial problems apart from health problems

Issues Faced by Down Syndrome Teenager's Parents

- Stress and worrying when they reach 10-12 years
- If the Child is non-judgmental
- Cannot do at the time what all others do in their career
- Embarrassment when peers make derogatory remarks

How Down syndrome can be managed?

A. Prenatal Testing:

This is a testing simply to identify whether the pregnancy is Down syndrome positive. A prenatal diagnosis of pregnancy with Down syndrome and proper information and education of the medicos to the pregnant mother enables her to choose to terminate the pregnancy. Denmark would be a country without a single Down syndrome citizen in the near future due to nationwide scheme from 2004. The studies reveal that California had a prenatal testing program since 1980's and its program reduces the childbirth from 1400 to 700 nos. halving their next generation with Down syndrome. Institute of Medicine (IOM) is a part of recommendation of prenatal test for no cost women well being visits for genetic or developmental conditions. Department for Health and Human Services was focused on using contraceptives services under the Patient Protection and Affordable Care Act under Obama care even though there was focus on Down syndrome .

Prenatal test for diabetes did not affect the negative impact on the pregnancy. There is no treatment for prenatal and postnatal of extra chromosome material that causes Down syndrome. Currently 4,00,000/- Americans have Down syndrome. **Characterizing prenatal testing for Down syndrome as “preventive care” expresses policy that fetuses diagnosed with Down syndrome should be prevented from being born.**

In China, prenatal testing is gaining importance among well off parents. Vineland Adaptive Behaviour Scales (VABS) are rarely used for investigation of developmental retardation in China. Children in china usually enter the elementary School at the age of 8 to 11 years. Learning in Special Schools provide sufficient opportunities to develop children’s potential. However, there is stagnation of development in Down syndrome children in Middle school level. Independent training of individuals and education to parents will only result in Adults with Down syndrome becoming less dependent on their families.

But PPACA under Obama care does not provide for Down syndrome the following:-

- Even though Prenatal testing done at no cost, PPACA does not provide for resources for informed decisions of mothers
- Adequate testing of health professionals on prenatal testing for individuals and families
- No accurate information about prenatal test and for Down syndrome patients
- Inadequate Access to Genetic Counsellors
- Referral to support organizations and professional guidance and federal law

B. Karyotype Testing:

This Karyotype test is done to the New Born to confirm diagnosis of Down syndrome. It is possible to screen Down syndrome at the time of pregnancy. Screening test estimates woman’s risk of having a child with Down syndrome. Diagnostic test reveals whether the fetus has Down syndrome. The most common prenatal testing are two blood test viz., Triple screen and other one is Alpha –Feta protein which is detailed in Sonogram (Ultrasound).

C. Chrionic Villus Sampling (CVs) and Peruntaneous Umbilical Blood Sampling (PUBS):

These two tests do not carry a small risk of miscarriage. CVs is performed exactly between 8 weeks and 12 weeks of pregnancy. Amniocentesis test is performed between 12 weeks and 20 weeks of pregnancy. PUBs are done after 20 weeks of pregnancy and these blood tests of women are more accurate and less risky.

Cognitive Development in China

Cognitive skill is matching of verbal mental age using Chinese version. The Child should identify banana from picture when interviewed by the interviewer. If raw score is 30 out of total score of 120, it means the Child is beyond 3 years and 3 months of age. No studies conducted in China are reported.

Comparison of Indian Scenario:

Down syndrome often comes with Congenital Heart Disease, which is treatable with surgery. But large number of Indian pediatricians does not go for surgery until the child reaches 10 kg of weight which is a misconception.

Early surgery is advised for Down syndrome children, as they are prone for pulmonary disorders, hypertension as per the study conducted by All India Institute of Medical Sciences and Sri Gangaram Hospital on 543 children affected by the Disease.

As per the statistics there are 23000 to 29000 children are born in India with Down syndrome, which is highest in the world. However, survival is only 44% of those who have congenital disease in the first year. In Western countries the Down syndrome infants with heart diseases, survival is 70%. Improved Life Expectancy in rich nations has been mainly attributed due to early surgical interventions and medical care.

The World Down Syndrome Day is observed on 21st March from the year 2011 by United Nations General Assembly. The said date is based on 21 chromosomes to signify the uniqueness of triplication (trisomy) and third month of the year, which signifies Down syndrome. Further, the Down Syndrome Day of the year 2015 is to be celebrated in India at Chennai.

Some of the Efforts taken in India to Support and Prevent Down syndrome

- i.** Down syndrome and Muchopoly Sacchhari doses (MPS). Mediscan trust is a non-profit charitable trust. Fetal Care Research Foundation (FCRF) in 1993 evolved strategies for preventive, curative and supportive care for children with Birth Disorders.
- ii.** MPS is a congenital metabolic defect affected children. MPS support group grown in number and parents meet regularly to exchange notes and coping with Children. The Support groups also helps careers, create awareness in school, neighborhood and relatives. They also provide wheel chairs.
- iii.** Birth Defects Registry of India (BDRI) is another venture to assess problems caused by birth defects in some parts of tamilnadu with many nodal centres in the State
- iv.** Preconception and Prenatal Diagnostic Techniques (PCPNDT) Rules was passed in good faith and would follow the spirit of law rather than letter of law. PCPNDT Rules is misused by Doctors and Lab Technicians as Money drives people to do abortive things who disclosed the sex. Prenatal diagnostics for sex determination is punishable offence, but yet girl child fetus aborting was reported widely. **Prenatal Diagnostic Techniques should be educative to the women undergoing abortion to prevent Down syndrome births like western countries instead of the relishing only ancient traditions.**

v. Special Legislations :-

In United States, there are Rehabilitation Act, 1973, Education of All Handicapped Children Act, 1975 and Americans with Disabilities Act, 1991.

There are no Special legislations in India but the laws applicable for Disabled is applicable for Down syndrome also. There is only one Legislation “Disabilities Act, 1995”.

Health Insurance Plan for Down syndrome in India

There is no separate Health Insurance plan available with public sector or private sector Insurers in India. In United States, the Insurance companies differ with Down Syndrome and a Healthy Child, but they get coverage through employer as it is a family cover. The Call centre assistance is provided for Down syndrome. If the Insured is self employed the child with Down syndrome will be removed from coverage as living in High risk category. Some of the States in America are covered through Medic aid whereas others get coverage through Private Insurers at a very higher premium as they are financially affordable.

➤ In India, the Union Ministry of Social Justice and Empowerment launched “Nirmaya Health Insurance Plan” for autism, central disabilities, mental retardation and multiple disabilities.

➤ Further National Insurance Identity cards are issued distributed by District Rehabilitation Department of each State Govt. and Tamilnadu Govt. gives Rs. 500/- as maintenance allowance per month.

But there are growing awareness and benefits offered viz.,

➤ Indian Railways provides a concession of 75% fare for disabled person travel with Escort. Bus concessions are given for travel including stay and School and for Disability / Day Care.

Further the latest statistics of 2014 reveal that India has 13,31,338 have impact of Down syndrome and China has 16,23,559 citizens with Down syndrome which are very alarming when compared to other western countries. In Western Countries are prevented from birth of Down syndrome , but in India our doctors try to regulate through education to pregnant women and beyond which they suggest for facing challenges of Down syndrome .

Suggestions for a Healthy India:

- ❖ Loving Home Environment
- ❖ Voluntary organisations for providing information and Support Services to parents of Down syndrome
- ❖ Adoption of District wise support services of Down Syndrome should be made as Corporate Social Responsibility and CSR shall form part of the Audit Report of Corporates.
- ❖ Physical Therapy and Strength of muscles e.g Horse riding bring the basic motor skills.
- ❖ Children with Down syndrome should undergo regular Health checkups
- ❖ Evaluated thyroid dysfunction and receive proper childhood immunisations
- ❖ Early attention and medical intervention
- ❖ Medical advancement for preventing Down syndrome birth
- ❖ Rural education and parental care
- ❖ Positive Attitude in Society to treat Down syndrome children as human beings
- ❖ Special Schools at affordable fees or Govt sponsored education and training in rural areas for Down syndrome.
- ❖ Special Insurance cover for cost of physio therapy, speech therapy etc, Down Syndrome Special School fees, Transportation, Special food, Medicines, Nursing, Training of parents and Literature.
- ❖ Indian women are averse towards abortion and sentimentally attached towards childbirth. In case of Down syndrome pregnancy, there should be proper education to pregnant women and the spouse in rural areas to avoid such improper growth in fetus.
- ❖ A State Level Trust has to be created for the Down syndrome to protect their life even after their parents' demise.

Conclusion:

The children with the problem of Down syndrome are able to participate in recreational, vocational, social activities and the adults with Down syndrome live jointly with their family and some live independently also. The opportunities for people with Down syndrome are great and there is no doubt to expect these individuals to make everlasting, positive contributions to the Society. Positive and strong mind of parents makes their child grow and overcome Down syndrome difficulties. Personal experiences of this author is that his own niece and one more friend's son were live examples of good parenting, adequate care and healthy atmosphere to face the challenges which have recovered them to a nearly normal child from Down syndrome . The crossing of adolescence create a strength for them to stabilize in their health conditions if adequate care and affection to the Down syndrome.



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