

Original article

**Life skills imparted to persons with Down syndrome –  
constraints and measures to sustain the use of skills learnt- A  
Qualitative study.**

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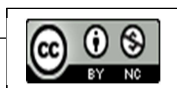
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**Abstract**

**Background:** Down syndrome a genetic disorder which is one of the causes of mental retardation and developmental delay. Imparting life skills as an early intervention helps the children and families to understand and meet the needs of their children. The objective of the study is to assess various life skills imparted, constraints faced in practicing skills learnt and measures to sustain the use of learnt skills.

**Methodology:** A Qualitative data was collected from 10 In-depth interviews (IDIs) and 6 Focus group discussions (FDGs) from parents and care givers of Down syndrome.

**Results:** Life skills for persons with Down syndrome is categorized into general and specific. Constrains faced include short attention span, uncooperative behaviour, communication problems, difficulty distinguishing between good and bad touch, health complications, and socializing issues. Addressing these requires raising awareness, providing access to specialized schools with trained professionals, ensuring health insurance coverage, and offering financial support and resources for families and caregivers.

**Conclusion:** Starting life skills at early age would help them have a better quality of life. A multi-disciplinary approach is needed to impart life skills to improve the quality of life in Downs syndrome. The access to improve speech and vocational therapy should be made available in all PHC's. Healthcare services for these persons need to be further streamlined to prevent stress of seeking a range of advanced laboratory tests and treatments from healthcare providers.

**Key words:** Basic Education, Down syndrome, Health insurance coverage, Specific Life skills, sexual education programme

**1. Introduction:**

Down syndrome is a condition in which a person have an extra chromosome. Chromosomes are fragments of genes in the body. They regulate the morphology and functions of how a child's body forms as it grows throughout pregnancy and after birth. An individual has 46 chromosomes at birth. Person with Down syndrome has an extra copy of one of these chromosomes called chromosome 21. A

medical term for having an extra copy of a chromosome is called 'trisomy'<sup>(1)</sup>. Down syndrome remains the most common chromosomal condition diagnosed globally. Every year, almost 6,000 babies born globally have Down syndrome. This means Down syndrome occurs in about 1 in every 700 babies<sup>(2)</sup>. A significant cause of mortality and morbidity in cities is congenital abnormalities and genetic diseases. An enormous number of

newborns with genetic diseases are born in India each year as a result of the country's high birth rate. Every year 21,000 newborns with Down syndrome, and over half a million babies with deformities<sup>(2)</sup>. In a multi-centric study, on the causes of referral for genetic counselling the top second disorders were identifiable syndromes which accounts (12.1%) like Down syndrome. In a more recent study in a private hospital the top reasons for referral were reproductive genetics (38.9%) comprising prenatal diagnosis and Down syndrome (9.1%)<sup>(3)</sup>. In a study of 94,910 infants in three Indian metropolises—Mumbai, Delhi, and Baroda—the incidence of Down syndrome was found to be 1 per 1150<sup>(4)</sup>.

Trisomy 21 also referred to as Down syndrome is the most prevalent chromosomal abnormality. Down syndrome is the commonest cause of mental retardation, developmental delay, learning and intellectual disability which is caused by genetic disorder. Few persons affected with Down syndrome are able to read, speak, and carry out their daily chores while the rest are unable to do so and require assistance. Studies show delayed speech development, short attention span, social withdrawal, impulsive behaviour and stubbornness are common in children with Down syndrome<sup>(5-7)</sup>. Early intervention services for Down syndrome are physical therapy, speech and language therapy, occupational therapy and other life skills<sup>(8,9)</sup>. Imparting life skills for these children as an early intervention will enhance the development of infants, toddlers, and help families to understand and meet the needs of their children and help them to be more independent. Life skill is defined "As abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life"<sup>(10)</sup>. Life skills also mean as the ability to adapt and to have positive behaviour that enable a person to face all the demands and challenges in his/her life<sup>(10)</sup>. Persons with Down syndrome encounter numerous challenges in learning and practicing new skills. Care givers need to be equipped to support person with Down syndrome to help them practice skills learnt. From this background, the objective of

this study was to comprehend the various life skills imparted to person with Down syndrome, to understand the constraints faced by person with Down syndrome in acquiring the skills and measures to sustain the acquired skills.

## **2. Methodology :**

A qualitative study design was chosen to explore and provide deeper insights. The study participants included teachers/ trainers of two special schools located in Chennai and parents and care givers of persons attending these special schools and were willing to participate in the study. The methods included In-depth interviews (IDI) and Focus group discussions (FGDs). IDIs and FGDs focussed on the various life skills imparted to persons with Down Syndrome, the barriers they face in learning the skills and challenges in practicing the skills acquired.

- 1. In-depth Interviews** - IDIs were conducted among parents, care givers and teachers/ trainer in special school. A guide was used to facilitate the process. Each IDI lasted for 20 – 30 mins. Data saturation was achieved after ten In-depth interviews with 5 parents, 3 caregivers and 2 teacher/ trainer in special schools.
- 2. Focus group Discussions-** FGDs were conducted among parents and with teacher/ trainer in special schools. FGDs were conducted by the researcher using a guide to facilitate the process and an assistant took notes on the nonverbal communication. Each FGD had around 8 to 10 participants and lasted for 45 mins to one hour. Totally six FGDs was conducted. Data saturation was achieved after three FGDs with parents and three FGDs with teacher/ trainer in special schools. Both IDIs and FGDs were audio recorded and later translated and transcribed. Data as analysed manually involving several interconnected stages beginning with: familiarization with data; identifying a thematic framework; indexing and sorting quotes and placing them under the appropriate thematic category; mapping; and final interpretation. Ethical approval was obtained from Institutional Ethical Committee of the tertiary medical college in Chennai. Informed written consent was obtained from all the study participants.

**Results**

**a. Various life skills imparted to the persons with Down syndrome**

Teachers / Trainers of life skills in special schools classified skills imparted to persons with Down syndrome into two main types - General skills and Specific life skills as shown in Fig:1.

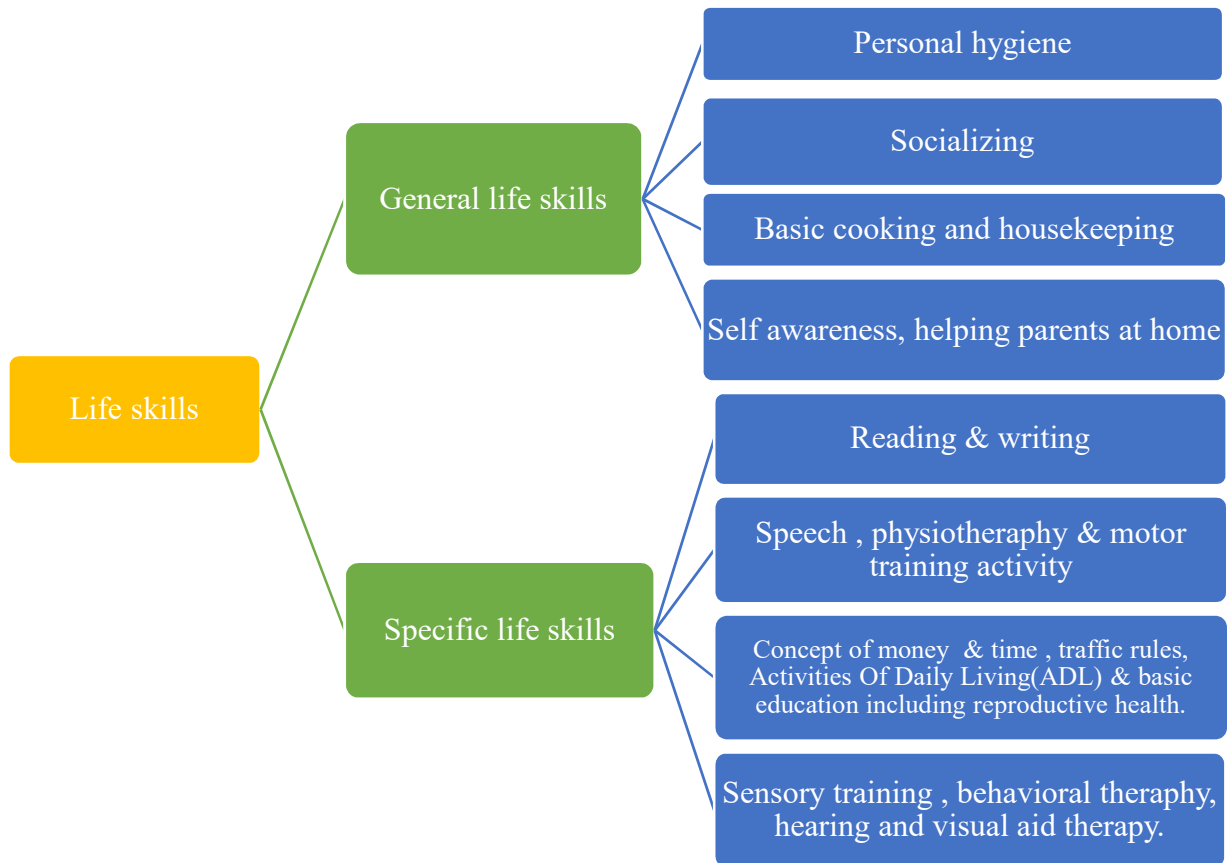


Fig.1: Various life skills imparted to the persons with Down syndrome

General skills include daily living skills like brushing teeth, bed making, personal hygiene(bathing), self-awareness, socializing, taking medication by self, combing hair, helping elders at home, basic cooking, housekeeping activities etc.Special skills like reading (vocabulary, word pronunciation) and writing, knowledge on concept of money, cycling, gardening, cooking, arts and crafts, basic education including reproductive health, speech therapy, Activities of Daily Living (ADL), candle making, motor activity training for kids, how to deal with adolescence behavior, special training for sensory issues, cooking food, behavioral

therapy, hearing and visual aid therapy, vocational training, road crossing, teaching about traffic rules, singing, dancing, keyboarding, swimming, social therapy etc.Many of the care givers and parents said that skills like brushing, proper eating habits, dressing habits were relatively easily followed by the persons with Down syndrome. Some of them are able to read, write, or perform other things that they have been trained in.

Many parents said that children with Down syndrome have delayed developmental milestones, therefore require special support and care like speech therapy, training on living skills, training to

improve motor activity, behavioural therapy, hearing and visual aid therapy.

Imparting special skills to persons with Down syndrome has helped to improve their quality of life. Some of the mother/Care givers shared their personal experiences. Simple measures like making the child stand in river mud mixed with water helps to improve the muscle tone and help then to stand for a longer time

A 38 years old mother said “My boy used to cry when he touches sand, as per the guidance of the

special school teacher, I took him to the beach and let him play in the beach in wet sand, he was not scary after that”

An experienced 45 years old special school trainer said, “Children with Down syndrome who have better IQs (Intelligent Quotient) receive formal education and can opt for certificate courses. Those with lower IQs are given vocational training. This training helps them find jobs, which is the main goal of the special schools.”

**b. Constraints in practicing skills learnt**

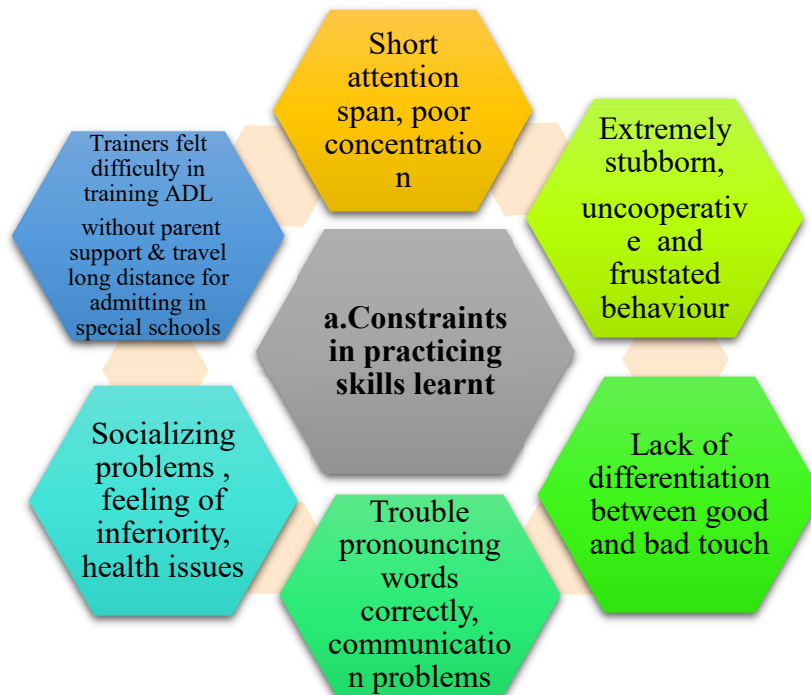


Fig 2: Various constraints in practicing the skills learnt

Persons with Down syndrome struggle to communicate and have problems focusing for long periods of time are frequently distracted, and can occasionally be obstinate as shown in Fig:2.

Children with Down syndrome usually have attention spans of less than 15 minutes are very uncooperative, and only participate in activities when they show an interest. They can adapt and learn despite being perhaps slow learners. It becomes hard to teach children when they get irritated since they will not follow any commands given to them.

35 years old special school teacher said “We can't treat these kids like normal children and be strict, we have to be friendly and teach them patiently, only then they will listen to us”.

Lack of understanding gender difference is another issue of concern shared by the teachers. Female children move close to male staff hug them and kiss them and express their love and affection. They do not understand what is right and wrong due to cognitive impairment.

42 years old teacher said “As they grow, we teach them what is good and bad, they just notice our feelings and

react, and this helps them to differentiate and protect themselves”.

Short attention span, poor listening capacity and need for repeated teaching to make them learn new things were common difficulties expressed by most of the care givers.

Trainers said that they must be kind to persons with Down syndrome, talk softly. While teaching them or training them to do something, they become extremely stubborn and won't listen to us if we become frustrated or shout at them.

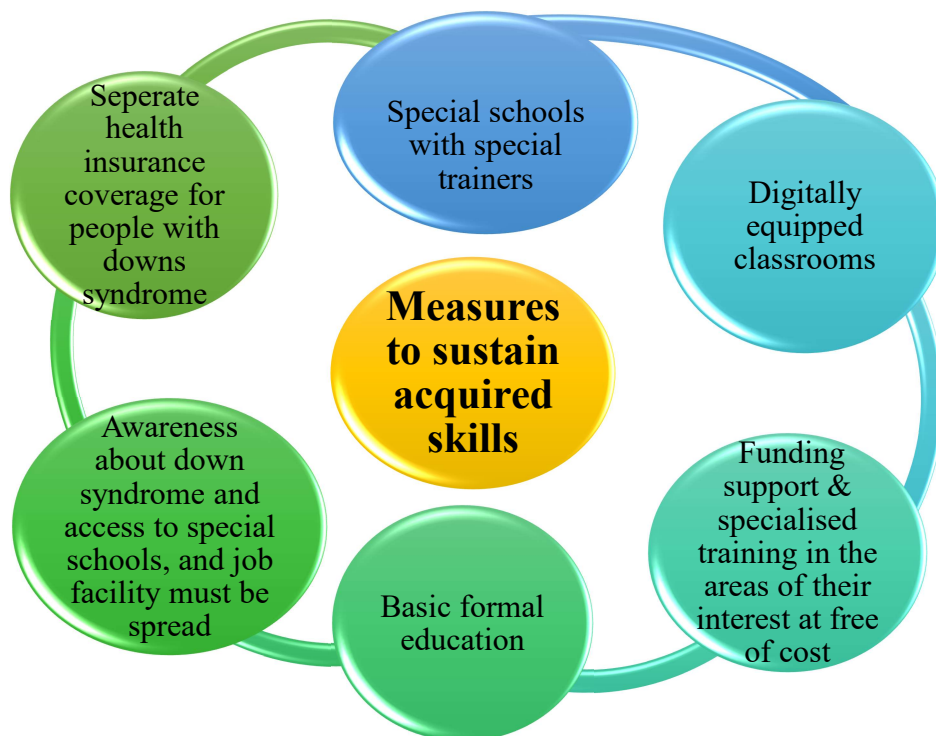
Many parents and care givers stated that these children felt slightly inferior while speaking with others because they have trouble pronouncing words correctly, which makes it difficult for them to express what they want to say.

Most of the special school teachers said that these children spend just 6-7 hours a day with them at school so it is difficult to completely train them. They added that ADL cannot be taught without parental support. As most of the skills like getting up early in the morning,

habits like brushing, bathing and eating on time, can only be taught at home. They educate parents on how to train their children at home, and this has to be followed. Care givers and parents stated these persons with Down syndrome face a lot of health issues like asthma, obesity, heart defects, cognition impairments, Musculo skeletal disorder's etc, which hinders them from learning new skills which are taught to them. Many parents stated that access to special schools in rural and semi urban areas are less, so for the betterment for their child future they have shifted from their native place to cities in search of special school or travel for long distance to get admitted in special schools for their Down syndrome child betterment.

A mother of 12 years old Down syndrome child said *“In my area there are no special schools available, so I had to travel a long distance with my child which is not possible, so I had to shift my home to the city for the purpose of my child's well-being.”*

**FIG 3) Measures to sustain acquired skills and support required for Down syndrome**



During IDIs, parents and care givers said special school play a vital role in teaching these children as these institutions have qualified instructors and trainers who can properly train these skills. Even

these specialised trainers teach parents how to encourage these kids in a positive way, so that the skills acquired is put in use, Care givers felt that government should support these persons with

Down syndrome. Fig:3 shows the various measures to sustain the use of skill learnt.

52 years old care giver opined *“The government is giving them money on a monthly basis, but would be good to provide these kids (children with Down syndrome) with additional financial assistance and to provide free enrolments in special schools to improving their quality of life.”*

29 years old mother added that *“A small percentage of Down syndrome children show interest in music and some in cooking, these children can be given some funding support and specialised training in the areas of their choice.”*

48 years trainer said that *“Digitally equipped classrooms will help them more effectively with hands-on experience and the possibility of including these in schools should be explored”.*

All the parents & caregivers of person with Down syndrome stated that basic formal education is very essential for Down syndrome. They also stated that every person with Down syndrome has a unique set of skills that must be discovered at a young age, and that the government and special schools must provide them with no-cost training in these skills so they can lead lives that are rewarding. Continuous training to persons with Down syndrome and also educating the parents to train them will only help them to practice the skills acquired. This becomes difficult for Down syndrome children born to low-income households who are not able to enrol in special schools.

Public awareness about Down syndrome is lacking, according to parents and care givers. Government and NGOs should raise awareness and start special schools with specialized educators to accommodate these children. Many parents believe their children quality of life is not up to par, despite admitting to government or private schools. 39 years old mother of the child said that *“My child was in a private school till 6 th standard, later the principal advised us to transfer my child to another school due to his persistent uncooperative behaviour and poor exam performance.”*

Special trainers emphasize the importance of reinforcement, rewarding, and positive attitudes in teaching these children. However, all of special trainers believe these children have health issues despite not having proper health insurance schemes. Many of these children have only CMCHIS, without private health insurance schemes.

### **Discussion:**

This discussion explores the various life skills acquired by Down syndrome persons, challenges faced by the parents, caregivers and individuals with Down syndrome in acquiring life skills, sustainable strategies that can be used to ensure their continuous use and utilization of the skills learnt.

### **Life skills imparted to Down syndrome:**

Our analysis on various life skills includes general skills which includes daily living skills like brushing teeth, bed making, personal hygiene, self-awareness, physical activity, socializing, communication skill were the most important life skills that are taught to the person with Down syndrome. A qualitative analysis of parental observations highlighted communication and physical movements are the important life skills learnt by Down syndrome these finding is similar to the research done by Nada Murphy et al <sup>(11)</sup> due to the understanding that communication and physical movements are significant life skills for individuals with Down syndrome can have practical implications for educational and therapeutic interventions.

From our analysis of specific skills, we found person with Down syndrome has difficulty in speech, conversing with others (socialization), word pronunciation and reading are affected because of poor oral language. These results implies the importance of early intervention and ongoing support to address these difficulties, potentially improving overall communication abilities and quality of life for individuals with Down syndrome which are consistent with the study findings done by Maja Roch et al <sup>(12)</sup>.

### **Constraints faced by Down syndrome:**

Persons with Down syndrome have difficulty in pronouncing words which hinders their speech, language and communication skills. Because of these reasons, persons with Down syndrome have difficulty in communicating with other people. A study done on social skills among overcome mentally retarded students showed concurrent results<sup>(13)</sup>.

Social skills play a vital role in developing the personal value of a person. These people when given proper intervention at early age can overcome this obstacle which will improve their quality of life. The person with Down syndrome also suffers from poor motor tone which inhibits them from doing normal day to day activities which is concurrent with the study findings done by Nada Murphy et al <sup>(11)</sup>

emphasizes the importance of a holistic approach in interventions, encompassing both social and motor skills, to provide individuals with Down syndrome the best possible support for optimal development. Owing to their sedentary lifestyles people with Down syndrome are more susceptible to modern lifestyle diseases like obesity, mental health issues, and musculoskeletal disorders. They also experience a great deal of physical stress which bring obstacles in their ability to acquire new life skills and in their physical activity. Female with Down syndrome deal with menstruation problems, which have a significant influence on everyday activities like limitations on going to schools and social engagement. These results are consistent with research conducted by Terri J. Pikora et al<sup>(14)</sup>. Proper self-care life skills for girls with Down syndrome, physiotherapy with proper muscle training activity under rehabilitation expert guidance would be helpful to overcome poor muscle tone. The parents of person with Down syndrome face lots of fear, discriminations and social stigma in the community which hinders the individuals with Down syndrome from socializing and developing social skills. Our results are similar to perceptions of parents with Down syndrome in a study done in Pakistan<sup>(15)</sup>.

***Measures to sustain to use of skill learnt:***

Person with Down syndrome generally have short attention span, but these persons generally have good attention in using modern electronic gadgets like phones, medias etc. These finding are similar to the study done Melek Demirel in Turkey<sup>(16,17)</sup>. Based on these results, developing individual education system based on the ability and intelligence levels would help them perform better in life. So, engaging them and teaching the right way to use modern electronic and media-based learning, visual and hearing aids by special trainers in special schools would be helpful for their betterment of life. These results are concurrent to the study findings done by Hendra Jaya et al<sup>(18)</sup>. Thus, the urgency of using media or digitally equipped class rooms for children with Down Syndrome, is expected to improve the quality of education and will also be useful in improving vocational skills in special schools and normal schools who have special trainers to train them.

Siblings born with Down syndrome have a stronger emotional bond, fostering a caring and concerned relationship. When taught basic life skills, even those with Down syndrome can easily learn from

their siblings, enabling them to sustain the use of these skills. This fosters a more positive and emotional bond between siblings. This will enable the person with Down syndrome learn and sustain the skills which are learnt<sup>(19)</sup>.

The persons with Down syndrome are affected with cardio vascular, respiratory, dermatological and behavioural problems. These people required more days of hospitalization when compared to general population which is similar to the results done by Ariel Tenenbaum et al<sup>(20)</sup>. Primary screening is done for all the comorbidities but in contrast to our study results parents claimed that they have to spend a lot of out-of-pocket expenditure for screening for Down syndrome. Insurance coverage is not available for persons with Down syndrome separately but they have government family insurance coverage and insurance for disability for certain medical diagnosis but not for Down syndrome persons. This contrast findings may be due to the need for healthcare policy improvements to ensure that necessary screenings for individuals with Down syndrome are accessible without imposing a significant financial burden on families.

Several studies done in various setting states that there is limited knowledge about Down syndrome and also stereotypical attitudes is present towards individual with Down syndrome among general public and community members than compared with health care workers and med students<sup>(19,20)</sup>. These findings are similar even in our study that the awareness and attitude about Down syndrome is limited among common people and in our community and we have also noted that there is lack of awareness about access to special schools in our study. The limited awareness and presence of stereotypical attitudes toward Down syndrome in the general public highlight the need for comprehensive educational programs, community engagement, and advocacy efforts. By addressing these challenges, there is an opportunity to promote a more informed, accepting, and inclusive society for individuals with Down syndrome.

***Conclusion and recommendations:***

Awareness regarding the various life skills imparted to persons with Down syndrome are adequate among parents and care givers but access to the special schools is low. Hence Adequate special schools should be opened to accommodate these children so that parents from low economic background can also have access to services provided by them which will also ease the travel

burden. Along with vocational training, children with Down syndrome should also receive basic school education in special schools. These children face many problems throughout their lives like delay in development, medical complications and doing their day to their activity and they are also prone to abuse. A multidisciplinary approach involving experts such as occupational therapists, speech pathologists, and mental health consultants can be helpful to parents, caregivers and trainers to impart

life skills, enhancing the quality of life. Comprehensive health insurance coverage, alongside existing government schemes, should be made accessible. Additionally, a robust social and sexual education program must be developed to meet their specific needs.

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