



# Association of Child Neurology-Indian Epilepsy Society Consensus Document on Social and Legal Aspects of Childhood Epilepsy (SOLACE)

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## Abstract

Epilepsy is a chronic neurological disorder which affects not only the health of the affected child, but also has an economic, psychological and emotional impact on the family as a whole. In the transition from Person with Disability (PWD) act (1995) to Rights of Persons with Disabilities act (RPWD act) (2016), which covers all aspects of life of a person with any disability, epilepsy has been excluded from the list of disorders, resulting in a loss of many of the benefits that were earlier available to persons with epilepsy, causing concern to all caregivers of persons with epilepsy. Additionally, physicians/ pediatricians/ neurologists are not really aware of the benefits that are available to persons with epilepsy, especially children. To address these issues, an expert group meeting of pediatric neurologists and epileptologists in India along with social workers/epilepsy educators legal experts, parents, and teachers was held. The implication of epilepsy being dropped as a disability, was discussed, and most of the experts concurred that epilepsy should be considered as a disability, depending of the type of seizures or the epilepsy syndrome. Also, the current status of income tax benefits, child care benefits, travel concession, schooling and health insurance for children with epilepsy in India were also discussed. The importance of creating awareness on these issues was stressed on. Here authors present the group consensus statement on these legal and social aspects about the care of children with epilepsy.

**Keywords** Childhood epilepsy · Civil rights · Children with disability · Disability evaluation

## Introduction

Epilepsy is one of the commonest chronic neurological disorders in children. In a population-based study among individuals in rural and urban districts of Bangalore, the prevalence rate of epilepsy was 883 per 1,00,000

population [1]. The median incidence of epilepsy in low and middle-income countries was estimated to be 81.7 (IQR 28.0–239.5) per 1,00,000 per year in a meta analysis performed to estimate the pooled incidence of epilepsy from published studies [2]. Epilepsy not only affects the health of the affected child but also has an economic, psychological and emotional impact on the family. There is a wide range of social and legal issues pertaining to care of children with epilepsy (CWE) (Fig. 1). The chronic nature of the condition, with one-third children being refractory to anticonvulsant drugs, frequent co-morbidities, shortage of pediatric neurologists and epileptologists, and limited access to quality health care services are some of the significant hurdles in the care of CWE in developing countries.

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## Process

The idea of preparing a document on the social and legal aspects of childhood epilepsy (SOLACE) was mooted by

**Fig. 1** Range of legal and social issues pertaining to children with epilepsy. *CCA* Child-care allowance; *CCL* Child-care leave; *CWE* Children with epilepsy; *RPWD* Rights of persons with disability act



members of Association of Child Neurology (AOCN). In association with Indian Epilepsy Society, a consensus document was envisaged on the same. The invited experts included eminent Pediatric Neurologists, Neurologists, Epilepsy educators or Special educators, parents of children with epilepsy, school representatives and legal advisors. A preliminary meeting to obtain inputs from epilepsy educators/special educators, parents, legal advisors and school representatives was held on 07 March 2018. Based on these inputs, scope of the topics was subdivided into six major headings: social benefits, social and legal aspects of epilepsy in infants/preschoolers, school aged children, adolescent school children, epilepsy counseling, and epilepsy with multiple disabilities.

The invited experts were categorized into one of the six groups with each group having representative from amongst Pediatric Neurologists, Adult Neurologists, Epilepsy educators, legal experts, and school representatives. The final list of scope of issues and the group distribution were mailed to all the participants. The assigned coordinator of each group reviewed the literature, prepared a draft of the document in consultation with other members. A final consensus meeting was held on 15th April 2018 at Delhi. The writer and coordinator of each group made a presentation of the draft document for consensus. Deliberations were held, and inputs and suggestions by the various participating members were

incorporated into the document. The final document was prepared and circulated to all the participating members. Table 1 summarizes the key recommendations of the group.

## Recommendations

### Epilepsy as Disability

A person with a disability is defined as “*a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others*” [3]. The Persons with Disabilities (PWD) Act (1995) included seven conditions that could be qualified as disabilities, but epilepsy was not included [4] (Table 2). However, further to this act, the guidelines for evaluation of various disabilities and procedure for certification, given by the Indian Gazette notification, 2001, made a provision for adding to percentage of disability in certification for Multiple Disabilities, and categorized epilepsy based on the frequency of seizures, despite being on adequate medication, into mild (only one convulsion), moderate (1–5 convulsions per month), severe (6–10 convulsions per month) and profound (more than ten convulsions per month [5] (Table 3). In 2016, Rights of Persons with

**Table 1** Key recommendations of SOLACE group for improving care of children with epilepsy

1. In the current scenario, drug resistant epilepsy or epilepsy with significant co-morbidities can be classified as a disability in the “chronic neurological disorder”. This will help the patients and caregivers to gain these benefits.
2. To include a neurologist or pediatric neurologist in the medical board certifying epilepsy, so as to ascertain the true intractability of epilepsy.
3. Inclusion of epilepsy as a disability would enable their parents to claim tax rebate under Section 80DD.
4. Working parents of children with epilepsy should be provided support for extra casual leaves, and child-care leave.
5. Inclusion of epilepsy as a disability would enable parents to claim the provisions of child-care allowances for disabled persons as per 7th Pay commission recommendations of Government of India.
6. The Maternity Benefit Amendment Act, 2017 should be implemented in every institution to establish day care facilities.
7. Children with epilepsy and their parents must be included as beneficiaries to receive the travel allowance.
8. Inclusion of epilepsy as a disability would enable parents to claim for non-transferrable job.
9. Need for effective redressal in case of discrimination of CWE in school.
10. Inclusion of epilepsy as a disability would enable parents to insure their medical expenses incurred during the course of treatment under some schemes.

CWE Children with epilepsy, SOLACE Social and legal aspects of childhood epilepsy

Disabilities (RPWD) Act 2016, a guideline for assessment and certification of a person with a disability, was passed, which has removed epilepsy as a disability [3]. Subsequently, the Central Government notified guidelines for assessment of disabilities. As per these guidelines, there are eight categories of conditions that can qualify as disabilities, with overall twenty-one disabilities included, but again, epilepsy *per se* was not included under any category [6]. These guidelines also

supersede the earlier guidelines of 2001, thus removing the provision for adding to disability percentage in multiple disabilities, if children had epilepsy as well.

Thus, in this transition from PWD act 1995 to the RPWD (2016), epilepsy as a specific condition is removed altogether. However, the RPWD bill has the provision for categorizing “chronic neurological conditions” as a disability both on its own as well in the list of conditions which if occurring in

**Table 2** Key points in Indian laws pertaining to care of children with epilepsy

Indian Laws/Acts pertaining to care of CWE	Key highlights	Aspects pertaining to epilepsy
Person with Disabilities act (Equal opportunities, protection of rights and full participation), 1995	Seven conditions: low vision, blindness, hearing impairment, locomotor impairment, mental retardation, and mental illness were considered as disabilities. It focuses on education, employment, non-discrimination, research and manpower development.	All neurological disorders were clubbed under locomotor/orthopedic disability. There is no mention of epilepsy or seizure in the act.
Rights of Persons with Disabilities (RPWD) act, 2016	The act came into effect from Dec. 2016. It covers 21 disabilities instead of only seven disabilities. It includes cerebral palsy, chronic neurological conditions, intellectual disability, locomotor disability, muscular dystrophy, multiple sclerosis, and speech and language disability. “Chronic neurological condition” as a condition that has its origin in some part of person’s nervous system lasting for a long period or marked by frequent recurrence. Ambiguity on duration of illness and frequency of recurrence.	Epilepsy has not been included for disability assessment and certification.
Gazette notification: Guidelines for Assessment of Extent of Disability and Certification of Specified Disabilities (Jan 2018)	These guidelines were issued for evaluation and certification of 12 newly identified disabilities as per RPWD act.	It mentions that “In persons with cerebral palsy, there may be other limitations like epilepsy. It needs to be assessed separately as per the guidelines and the final disability % calculated using the combining formula: $a + b(90-a)/90$ (a = higher value, b = lower value)”. However, how to calculate the disability scores for epilepsy is missing in guidelines which were present in earlier notifications. Moreover, epilepsy alone does not qualify for disability.

CWE Children with epilepsy

**Table 3** Guidelines for certification of epilepsy as per notification June 2001 (Government of India)

Frequency of convulsion	Severity	Percent disability
Only one convulsion	Mild	Nil
1–5 convulsions per month on adequate medication	Moderate	25%
6–10 convulsions per month on adequate medication	Severe	50%
More than 10 convulsions per month	Profound	75%

Total disability =  $a + b(90-a)/90$  (a = higher score; b = lower score) [maximum score cannot exceed 100%]. In case of multiple disabilities, it will be arranged from highest to lowest and disability score calculated using above formula in sequence

combination, would qualify for multiple disabilities. A Chronic neurological condition is a condition that has its origin in some part of a person's nervous system, and lasts for an extended period or is marked by frequent recurrence [3]. Although epilepsy would fit into this category, the bill fails to specify the duration of illness or to define the frequency of recurrence. Hence, despite epilepsy being significant comorbidity to intellectual disability, it fails to add to the final disability scoring among children with multiple disabilities. This often underestimates the final disability.

In a recent Gazette notification by Government of India (dated 22nd October 2018), Rights of Persons with Disability rules were amended and called as Right of Person with Disability (Amendment Rules), 2018 [7]. Assessment for high support need is based on six points: severity of physical disability (max score = 25), severity of mental disability (max score = 25), extent to which daily activity is impaired (max score = 35), cognitive abilities for self care (max score = 5), environmental barrier, and socioeconomic status (BPL card holder) (max score = 5). Any person with benchmark disability with a score of 60 out of 100 may be recommended for high support need. This amendment although does not talk about epilepsy. However, a child with epilepsy having marked functional impairment for performance of daily activity can score a fair chance to receive high support needs despite low scores in physical and mental disabilities.

### Group Recommendations

1. Drug resistant epilepsy or epilepsy with significant comorbidities can be classified as a disability in the "Chronic neurological disorder" category of disabilities in RPWD act, 2016. In other cases, if the existence of epilepsy is causing a significant impact on the quality of life, for any reason, e.g., major side effects of drugs, school attendance, deterioration in scholastic performance and others, temporary disability may be awarded at the discretion of the board. This may be based on inputs from caregivers, school teachers, or school report cards, which may be submitted to the board.
2. The existing earlier categorization of epilepsy (Gazette notification 2001) into mild, moderate, severe and

profound was simple to use and easy for certification; thus, it can still be used for assigning of disability as well as adding to disability in children with multiple disabilities.

3. Epilepsy may remain uncontrolled on wrong choice or wrong dose of the antiepileptic drug. For *example*, a child with juvenile absence seizure may have more than ten convulsions a day on phenytoin quantifying his epilepsy to be classified as profound. Hence, it would be prudent to include a neurologist or pediatric neurologist in the medical board certifying epilepsy as a disability, to ascertain the true intractability of epilepsy.
4. Certification into temporary or permanent disability should be decided on a case to case basis. Children with epileptic encephalopathy, epilepsy with co-morbid global developmental delay and intellectual disability are often categorized as "permanent disability".

### Income Tax Benefit in Epilepsy

Section 80 U provides tax benefits to individuals with a disability, and Section 80DD deals with benefits to individuals (parents) whose dependent family member (child) has disability [8]. Any individual or a parent taking care of medical expenses of a dependent person (child) with a disability can get a tax deduction of INR 75,000 (if landmark disability: at least 40% disability) or INR 1,25,000 (severe disability: more than 80% disability). Disabilities covered under Section 80DD include cerebral palsy, autism, locomotor disabilities, hearing impairment, intellectual disability, and multiple disabilities [8]. However, epilepsy alone has not been considered as a disability in Section 80DD. Parents need three documents: medical disability certificate, form 10-IA, and self-declaration certificate stating medical expenses for medical treatment, training, and rehabilitation for claims under Section 80DD.

### Group Recommendations

1. The majority of children with epilepsy with multiple disabilities have drug-resistant epilepsy requiring various, costly antiepileptic drugs. The inclusion of epilepsy as a

disability in the (RPWD) Act 2016 under Chronic neurological disabilities would enable their parents to claim tax rebate under Section 80DD.

2. Parents of children with epilepsy and multiple disabilities must be made aware of this tax rebate by doctors, social workers or other support groups and organizations working for people with epilepsy.

### Child-Care Allowance and Leave

Carer's allowance refers to compensation given to a caregiver for taking care of a person with a disability. This allowance would help with the extra cost of looking after a child who has a disability or a health condition which requires substantial care. This concept is prevalent in the United Kingdom, Scotland, and Australia [9], where these are available to all affected persons. In India, there is no provision for any financial child-care allowance. However, as per the 7th Central Pay Commission, all mothers employed by the central government are entitled to child-care leave for a period of 2 y, till the child (up to two children) is 18 y, with three spells in a single calendar year [10]. Additionally, mothers with disability above 40% employed in the government sector are provided with child-care allowance after childbirth to the tune of Rs. 3000 per month to cover expenditure on infant care [11]. This is given from the time of birth till the child is 2 y of age [11]. Also, a special allowance for child education and hostel subsidy is granted to government employees having children with disability. All employees are paid Rs. 2250 per month as children education allowance and Rs 6750 rupees per month as hostel subsidy, but these benefits are doubled for parents of children with disability [12]. Similar provisions are not available to employees in the private sector.

#### Group Recommendations

1. Working parents of children with disability should be provided support with extra casual leaves, child-care leave in the private sector as well.
2. Carers allowance for caretakers of children with disability in both the government and private sector is desirable. However, there are significant limitations in providing carer's benefit in India as the healthcare system in countries where carers allowance is provided are entirely insured by the government.

### Daycare Services

Daycare services have a crucial role for working parents with comprehensive facility for managing children with epilepsy [13]. Persons trained in administering prescribed medications

and use of first aid measure to handle and manage acute seizures is desirable. Given the shortage of staff, often many daycare centers refuse to admit children with special needs including those with epilepsy. The Maternity Benefit Amendment Act, 2017 states that employers with more than 50 employees need to have a daycare, but it has not been appropriately implemented [14]. A majority of workplaces do not have daycare center facilities for children of their employees.

#### Group Recommendations

The Maternity Benefit Amendment Act, 2017 should be implemented in every institution to establish daycare facilities. Existing daycare services should not deny admissions to children with epilepsy and must be equipped to handle children with epilepsy.

### Care in Nuclear Families

Respite is required among parents of children with multiple disabilities in nuclear families with working parents. The social worker would immensely benefit and help parents in providing continued care of their child even during their working hours and absence. They could coordinate with agencies/ non-governmental organizations/crèche services that could render their help for working parents. As mentioned earlier, the majority of workplaces lack facility for crèches in their premises. The cost of hiring full or part time help is a significant limitation in nuclear families. This often results in absenteeism from work and often forces the mother to leave her career options to take care of her baby/child.

#### Group Recommendations

Provision for child-care leave and other types of leaves for mothers of children with a disability could be considered on priority. The Maternity Benefit Amendment Act, 2017 should be implemented in every institution to establish daycare facilities. Existing daycare services should not deny admissions to children with epilepsy and must be equipped to handle children with epilepsy.

### Travel Concession

Travel concessions issued by central and state government for disabled are restricted to blind persons, orthopedically handicapped persons, deaf and dumb persons and mentally retarded persons. They are entitled to 75% concession for travel in 3 tier, 2 tier and 1st class AC trains [15]. Indian Airlines allow 50% concessional fare to blind persons alone [16]. Epilepsy in isolation or as a part of multiple disabilities is

not included in the list of beneficiaries for both train and air travel. No concession for accompanying person is allowed.

### Group Recommendations

1. Children with epilepsy must be included as a beneficiary to receive the travel allowance.
2. The travel allowance entitled for central and state government employees should be extended to employees in the private sector.
3. The travel allowance benefits should also include bus travel and metro trains.
4. Concession benefit should be extended to the affected individual as well as one accompanying person.

### Preferential Posting of Government Employee

In a notice issued by the Ministry of Personal, Public Grievances and Pension (6th June 2014), any Government servant who is a caregiver of a child with disability is exempted from the exercise of rotational transfer [17]. This order was issued to respect that parents raise a support system for the affected child over a period of the time in the locality where he resides, which helps them in rehabilitation. However, the word “disabled” in the notice includes seven disabilities excluding epilepsy.

### Group Recommendations

The inclusion of epilepsy as a disability would enable parents to claim for non-transferrable job. This would also ensure proper compliance with treatment and regular follow-up and rehabilitation.

### Customs Concession

The central government of India exempts specified goods when imported into India by a disabled person for his/her personal use [18]. However, there is no exemption for some of the proven or experimental drugs to India for conditions including those with epilepsy.

### Group Recommendations

There are a lot of newer antiepileptic drugs like vigabatrin, stiripentol, rufinamide, and quinidine that are imported from other countries at a very high cost. There could be governmental measures to subsidize the import cost of these drugs for poor patients with epilepsy.

### Schooling

Sarva Shiksha Abhiyaan (SSA) focuses on providing elementary education to all children including children with disabilities [19]. It intends to provide inclusive education to children with special needs (CWSN) where both children with disability and typically developing ones learn together in the same class. It includes support for engagement of special teachers, training teachers using modules to deal with children with special needs, equipping resource rooms, and making the school barrier-free. Although, this might be useful to children with multiple disabilities who have associated epilepsy, it largely excludes those with isolated epilepsy. Children with epilepsy are also vulnerable and may have high support needs in the form of remedial teaching, shadow teachers, occupational as well as various other therapies, writers, and travel cost to the school. Children with epilepsy cannot be refused admission under the right to education act [20]. In case of discrimination or refusal to admit, one can approach the State Commissioner of Disability or can contact Chief Commissioner for Disability [21]. The main concern about this is that epilepsy is still not a disability.

### Group Recommendations

1. Considering the burden of childhood epilepsy and phenomenal cost of most of the long-term antiepileptic drugs, it would be wise to seek for an educational concession even for children with epilepsy alone and include children with epilepsy as one of the beneficiaries in SSA.
2. School staff and teachers must be sensitized to care of children with epilepsy. School should be equipped with first aid measures to handle seizures. School staff and teachers may be trained to handle seizures, ensure drug compliance, encourage buddy system, and develop liaison with local hospital in case of medical emergency.
3. If the child is forced to leave the school on the basis of his/her epilepsy, there should be an accessible redressal pathway for the family. For *example*, parents can explore the option of grievance redressal with the disability commissioner.

### Health Insurance

#### Niramaya

Niramaya is a health insurance scheme of National Trust for persons with disabilities [22]. The disabilities covered include autism, cerebral palsy, mental retardation and multiple disabilities. It provides coverage of up to one lakh rupees per year for prevention and reduction of impairments, both OPD and in-patient, on a reimbursement basis.

## Swavlamban

Swavlamban health insurance scheme for persons with disabilities was launched by The New India Assurance Company Limited in association with the Ministry of Social Justice, Department of Social Justice [23]. Parents of PWDs are covered for a maximum sum of two lakh rupees. However, epilepsy is not considered a disability for this claim.

## Insurance Regulatory and Development Authority of India (IRDAI)

The Insurance Regulatory and Development Authority of India constituted a working group for standardization of exclusions in health Insurance contracts in July 2018 [24]. As per these recommendations, *epilepsy* is included in the list of permitted permanent exclusions. The list has 17 conditions which can fall into the category of permanent exclusions. This list may be changed annually by the IRDAI, depending upon changes in perceptions.

This can impact insurance for children and persons with epilepsy in the following ways:

- (a) If epilepsy develops after inception of the policy: As per the recommendations, all health conditions acquired after policy inception should be covered under the policy and cannot be excluded. Thus if a child develops epilepsy after the policy comes into effect, he/she will be covered fully. However, most of them would refrain from delivering the cost of outpatient services, as is the case for all other conditions as well.
- (b) Insurance, if a child or person is known to have epilepsy at the time of taking the policy: Till now a person with epilepsy could not obtain any insurance at all, as any person having a pre-existing disorder which was mentioned in the permanent exclusion list, could not be insured.

However, with the present the IRDAI working group recommendations, health insurance may be obtained by disclosing the epilepsy at the time of taking the policy; treatment for epilepsy would be excluded, as it is named in the list of conditions in the permanent exclusions, but treatment for other conditions can be covered from the day of inception. *E.g.*, if a child with epilepsy develops pneumonia, treatment cost pertaining to pneumonia would be covered under the policy and not epilepsy related treatment cost. A written consent of the person with epilepsy or parents of child with epilepsy would be required at the time of enrolling into the plan.

Medical practitioners must also be aware that the use of the word “genetic” in clinical diagnosis as in “genetic epilepsy” often results in rejection of insurance claims. As all genetic disorders are included in the list of permanent exclusions by IRDAI, giving a diagnosis of genetic epilepsy must be done with care, as the current status of insurance claims for these

disorders is not clear. Thus before taking any insurance plan, the parents must go through in detail about the type of policy and the exclusions, so that they are not denied claims later.

## Group Recommendations

1. The inclusion of epilepsy as a disability would enable parents to insure their medical expenses incurred during the course of treatment. The group intends to suggest removal of epilepsy as a permanent exclusion for health insurers.
2. In case where epilepsy can be declared as cured as per definition by ILAE, epilepsy should not be a pre-existing disorder and neither should it be on the list of permanent exclusions.
3. Genetic epilepsies diagnosed after the insurance plan is instituted should not face rejection of claims, on ground that it is was pre-existing, as many genetic epilepsies manifest later in life.

## Air Travel

International Air Travel Association (IATA) medical guidelines say that if a person has a tonic-clonic seizure less than 24 h before the flight, he would need medical clearance to be allowed to fly [25]. If seizures are generally well controlled, medical approval is usually not required. Airlines’ medical policy should be checked, and airlines should be informed of epilepsy status before and during travel.

There are no additional legal or support systems, or special guidelines peculiar for children with epilepsy in this age-group regarding air travel; the guidelines applied are the same as for adults. Since children are usually accompanied by parents who are familiar with emergency seizure management for the child, it is likely safer as compared to adults travelling unaccompanied. For children travelling alone under care of flight attendants, disclosure about the child’s condition and emergency management must be explained to the airline staff on the flight before travel. Parents must be educated to avoid triggers like prolonged fasting, sleep deprivation or missing scheduled antiepileptic medication. Parents must carry the doctor’s prescription along with rescue medication.

## Group Recommendations

1. The airline services should be equipped with midazolam nasal spray/first-aid management of a prolonged seizure.
2. The airline staff should be trained for first-aid for seizure management.
3. Airlines medical policy should be checked and airlines should be informed of epilepsy status before and during travel.

## Transferring from Pediatric to Adult Medical Care

The majority of hospitals in India have extended pediatric care till 14–18 y age. Transition to adult medical care beyond the age of 18 y for children with multiple disabilities is quite challenging. There are neither transition clinics nor any effective mechanisms to transfer pediatric cases to an adult neurologist. The timing of transition could begin early among children with chronic and severe epilepsy like Lennox Gastaut syndrome. In a study, it has been shown that nearly 22% of these young adults were still in pediatric care and 22% had no care coordinators [26]. Hence, transfer of responsibility is essential to ensure a smooth transition without dropouts.

Transition clinics in adult neurology have been suggested by a few authors where both the pediatric neurologist and adult neurologist address their issues [27]. Large numbers of adult neurologists are somewhat uncomfortable with patients who have intellectual disability. Involvement of nurse specialists or epilepsy educators, if available, during the transition would be beneficial considering better approachability of the nurse when compared to a physician. Relationship of the social worker could address the psychosocial problems for patients and relatives. A joint consultation between pediatric and adult neurologist with pediatrician/pediatric neurologist providing a written complete transfer summary of the patient with multiple disabilities would be useful.

## Group Recommendations

A majority of the Indian patients are under follow-up of multiple physicians; it thus becomes challenging to establish the transition from Pediatric to Adult Neurology care. It is thus desirable that the general practitioner or pediatrician who knows the family best coordinates with a specialist as and when required. Ideally, the shift should occur under the supervision of someone who is locally available, for best continuity of care.

## Parent Support Groups

The impact of epilepsy diagnosis on family includes stress, depression and anxiety levels. These factors often lead to parental reluctance to seek professional help [28]. Creation of a parent support group and interventions targeted at parents of children with disability to manage their child's behavior have shown promising results and is cost-effective, especially in resource-limited settings. Parent to parent counseling sessions enable parents to help other parents in analyzing the ability rather than disability. At present, there are only a few national level parent support groups for majority of children with different neurological disorders, including epilepsy.

## Group Recommendations

Majority of the parent support groups in India and abroad are initiated by parents. All parents must be encouraged to create and participate in such parent support groups for children with epilepsy, actively. Written information pertinent to the condition must be provided; condition specific resource material as patient information sheets would help parents go through relevant literature rather than building knowledge through stray or anecdotal experiences shared in the public domain. Some centers have published patient information sheets for disease-specific conditions like cerebral palsy, Duchenne muscular dystrophy and so on, and such material needs to be prepared for epilepsy in children as well. All resource material should be generated in the local language as well.

## Conclusions

Children with epilepsy need appropriate social and legal support. Reintroducing epilepsy as a disability in Indian health system is strongly recommended. This would enable parents to claim entitled tax benefits, train and air travel concessions, health insurance, child-care allowances and child-care leave. In the current scenario, classifying epilepsy as a chronic neurological disorder will help the patients and caregivers to gain these benefits. Pediatricians and neurologists who care for children with epilepsy need to be aware of the various schemes provided by the government so that they can guide the parents appropriately. In addition, establishment of day care services, smooth transition to adult care, creation of parent support group and provision of resource material for parents of children with epilepsy will improve the social acceptance and quality of life.

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## Compliance with Ethical Standards

**Conflict of Interest** None.

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