



# Students with Epilepsy in Schools: An Inclusion Imperative

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Schools are microcosms of society, capable of significantly impacting the lives of students with epilepsy through information, participation, inclusion, and support. The World Health Organization recognizes the strong link between schools and health.<sup>1</sup> Epilepsy, a prevalent childhood neurological disorder affecting approximately 6 in 1,000 students, poses humongous challenges.<sup>2</sup> Point prevalence is 5.2 per 1000 in the 0- to 9-year age group and increases to 8.9 per 1000 in the 10- to 19-year age group.<sup>3</sup> India, with an estimated 10 million epilepsy cases, has a substantially affected child population.<sup>4,5</sup> School-based surveys report epilepsy prevalence rates ranging from 4 to 7.9 per 1,000 children.<sup>6,7</sup>

Schools are pivotal in children's development, influencing peer relationships, social interactions, academic achievement, cognitive progress, emotional regulation, behavior, and physical and moral development. Epilepsy and its comorbidities reciprocally affect these areas, highlighting the complexity of managing epilepsy within the school environment. Notably, approximately one-third of seizures occur at schools.<sup>8</sup>

India's National Education Policy 2020 (NEP 2020) has brought inclusive education for children with disabilities, including those with epilepsy, by outlining a framework for disability-inclusive teacher training modules, the appointment of specialist educators, and the establishment of resource schools to enhance educational opportunities for all.<sup>9</sup> However, inclusion for students with epilepsy extends beyond mere mainstreaming. Schools must foster a culture of acceptance and understanding, educating students and staff about epilepsy, dispelling misconceptions, and nurturing empathy. Teacher training modules equip educators to recognize seizures, administer first aid, and optimize classroom

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environments to minimize seizure triggers, creating a supportive ecosystem for students with epilepsy.<sup>10</sup>

Children with epilepsy (CWE) encounter substantial challenges in the school environment owed to limited awareness, misconceptions, and misunderstandings about the condition. While sharing similarities with adult ordeals, childhood epilepsy stigma presents unique challenges, including negative stereotypes, identity conflicts within oneself, institutions, and the community, and a particularly severe impact on children, families, and health care services. Stigma profoundly impacts the quality of life for CWE and poses substantial obstacles for them within the school milieu.<sup>11</sup>

Fear of seizures, coupled with inadequate information, often leads to discrimination and isolation.<sup>12</sup> Peer misconceptions can foster avoidance and social exclusion, and on top of that, teachers with inept knowledge and training may struggle to create supportive and inclusive classrooms. Conversely, excessive overprotection or restrictions can hinder a student's growth. Confluent, these factors deplete self-esteem, decrease motivation, devastate academic performance, and eventually exacerbate school absenteeism, substantiated by abysmal attendance records in 30 to 88% of cases.<sup>13,14</sup> Research indicates that school attendance is an impediment, with 50% of CWE displaying erratic attendance owing to a catalog of factors, including ongoing seizures, learning difficulties, behavioral issues, and limited school accessibility.<sup>13</sup> Moreover, the impact extends beyond the child with epilepsy; when a sibling is affected, absenteeism rates among unaffected siblings reach up to 13%.<sup>14</sup> Ensuring their full inclusion in academic and social life is a moral imperative for their academic success and well-being.

Students with epilepsy are an educationally vulnerable group, and a substantial proportion of these children struggle

DOI <https://doi.org/10.1055/s-0044-1790251>.  
ISSN 2213-6320.

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with academics, with underachievement rates ranging from 10 to 54%.<sup>15,16</sup> Intellectual impairment, seizure severity, underlying brain abnormalities, seizure control, socioeconomic factors, and parental education contribute to these challenges.<sup>16,17</sup>

Comorbidities significantly impact academic performance. A nationwide registry found that 80% of CWE had at least one comorbidity.<sup>18</sup> Intellectual disability is most common, followed by specific learning disabilities like dyslexia (13–32%), dysgraphia (35–56%), and dyscalculia (20–38%).<sup>19,20</sup> These learning difficulties can persist into adulthood, affecting long-term educational and occupational outcomes.<sup>20</sup>

Psychiatric comorbidities pose a substantial burden. Anxiety disorders and depression are reported in 19% (95% confidence interval [CI]: 12–29%) and 13.5% (95% CI: 9%–20%) of youth with epilepsy, respectively.<sup>21</sup> Suicidal ideation is reported in 8 to 20% of pediatric epilepsy, with an additional psychiatric diagnosis increasing the risk by 80%.<sup>22,23</sup> Beyond academic challenges and psychiatric comorbidities, epilepsy restricts extracurricular involvement. A survey found that 18% of young people with epilepsy are excluded from school activities.<sup>24</sup> While the International League Against Epilepsy (ILAE) Task Force on Sports and Epilepsy provides guidelines, caution is recommended for high-risk activities.<sup>25</sup>

Open communication and collaboration among parents, health care professionals, and educators are crucial. Individualized education programs (IEPs) that address specific needs and outline seizure management protocols can ensure a coordinated approach. Schools should also explore resources and support groups to empower students with epilepsy and address their social and emotional challenges. A whole-child approach is essential for teachers as they develop teaching plans and educational solutions. This collaborative effort requires a strong commitment from health care providers, families, educators, and, most importantly, the children.<sup>1</sup>

Unfortunately, negative attitudes toward epilepsy can deprive children of educational opportunities, with some schools even refusing admission. While legislation in certain countries prohibits such discrimination, consistent implementation remains crucial.<sup>26</sup> A systematic review found deficiencies in teachers' knowledge and hesitancy toward including CWE in extracurricular activities.<sup>27</sup> This reluctance often stems from a lack of training in providing seizure first aid. However, research offers a compelling solution. Educational interventions for school teachers worldwide have significantly improved their understanding, acceptance, and ability to support CWE.<sup>10,27</sup> Studies conducted in India, Nigeria, Lebanon, and other countries demonstrated that training programs, ranging from short sessions to 2-day program initiatives, effectively improved teachers' knowledge of epilepsy.<sup>27</sup> These programs also empowered teachers to confidently include CWE in classrooms and extracurricular activities, equipped them with first-aid skills for seizures, and reduced their concerns about potential repercussions.<sup>10,27</sup>

Our research reinforces the importance of sustained training. While a 1-day workshop yielded some positive results,<sup>10</sup> a 2-year longitudinal program in the Faridkot district in North India significantly improved teachers'

knowledge, attitudes, and practices regarding epilepsy. This long-term approach facilitated early detection through national health programs and fostered a more supportive school environment (unpublished data).

Integrating CWE into the educational system necessitates incorporating epilepsy awareness and management into teacher training curriculums.<sup>1,10</sup> Additionally, several global initiatives support CWE in schools, including Epilepsy Society in the United Kingdom.<sup>24</sup>

Schools serve as invaluable platforms for delivering school-based educational interventions that can significantly enhance epilepsy management by educating students, teachers, and peers. Investments in school-based programs can improve awareness, social interactions, and overall experience for CWE while reducing social and psychological stigma, discrimination, and prejudice. Beyond improving the quality of life for CWE, these interventions offer broader societal benefits, including lower dropout rates, enhanced educational outcomes, and increased future employment and productivity. Implementing inclusive strategies within schools is paramount. This involves educating school authorities and teachers about epilepsy, developing individualized seizure management plans, providing supervised medication access, accommodating the specific needs of CWE, fostering peer acceptance, ensuring emergency preparedness, and promoting effective communication among all stakeholders.<sup>10,27</sup> Interventions should prioritize timely enrolment, reduced school dropout rates, re-enrollment options based on neuropsychological assessments, and alternative education pathways.

The benefits of inclusion in schools are multifaceted. Supported and accepted students with epilepsy are empowered to excel academically and socially and reach their full potential. Positive school experiences build self-confidence, independence, and a sense of belonging, which are crucial for overall development. Inclusive schools can serve as models for broader societal acceptance of epilepsy. In resource-constrained nations like India, the simultaneous engagement of school teachers, administrators, parents, and students is crucial in implementing interventions. This collective effort can pave the way for establishing "Epilepsy Smart Schools."

### Funding

None.

### Conflict of Interest

None declared.

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