



A Study on Awareness and Benefits of Government Schemes for Parents of Children with Special Challenges.

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Abstract

Children with special challenges require additional support and resources to ensure their holistic development. Governments worldwide have implemented various schemes and programs to assist parents in providing the best possible care for their children with special needs. This research paper aims to investigate the awareness levels among parents regarding government schemes designed for children with special challenges and to analyze the perceived benefits of these initiatives. The study will contribute valuable insights into the effectiveness of existing programs and identify areas for improvement to enhance the overall well-being of children with special needs and their families.

Keywords: Children, Parents, Special Challenges, Benefits, Government Schemes.

Introduction:

Children with special challenges, encompassing a spectrum of disabilities, developmental disorders, and learning difficulties, navigate a unique journey that demands specialized attention and care. Recognizing the importance of fostering an inclusive society and providing comprehensive support for these children, governments worldwide have instituted a variety of schemes and programs. These initiatives aim to alleviate the challenges faced by families with children possessing special needs, with a focus on fostering their overall development and well-being.

However, the success of these well-intentioned government programs hinges significantly on the extent to which parents, as primary caregivers, are aware of and engaged with these initiatives. The effectiveness of these schemes is intrinsically linked to the awareness levels among parents, who play a pivotal role in the holistic development of their children with special challenges.

This research endeavors to delve into the awareness levels among parents regarding government schemes designed for children with special challenges. Moreover, it seeks to unravel the perceived benefits of these initiatives as experienced by parents. By examining the

interplay between parental awareness and the effectiveness of existing programs, this study aims to contribute nuanced insights that can guide policymakers and stakeholders in refining and enhancing the support systems in place.

Background:

Children with special challenges often require not only medical and therapeutic interventions but also a network of societal support and understanding. Governments globally have recognized the importance of developing and implementing targeted schemes to address the multifaceted needs of these children and their families. These schemes encompass a spectrum of services, including healthcare, education, and social support, with the overarching goal of fostering an inclusive environment that enables every child to reach their full potential.

Despite the implementation of these initiatives, the success of such programs is contingent on the awareness levels among parents. The lack of awareness may lead to underutilization of available resources, hindering the intended positive impact on the lives of these children. Consequently, understanding the factors influencing parental awareness and the perceived benefits of government schemes is crucial for refining and optimizing the support systems in place.1.2

Literature review

Atkinson (2010) state that the major causes of neurological disorders are unclear, although LDs can be triggered by various factors such as prenatal and birth problems. However, what do seem to be clear are the cross-cutting challenges that are inherent in parenting a child with learning disabilities.

Van Pletzen and Lorenzo (2015) argue that family attitudes and behaviour prevent persons with disabilities from developing to their full potential. Promoting independence and stimulating potential in persons with disabilities proposes the opposite, thereby endorsing the social model of disability.

Harper et al. (2013) point out that there are wide-ranging challenges that are integral to parenting a child with LDs. Children with learning disabilities generally require more attention because they may have additional needs when compared to nondisabled children

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Objectives of the Study:

1. To assess the awareness levels among parents regarding government schemes for children with special challenges.
2. To examine the perceived benefits of existing government programs among parents.
3. To identify challenges and gaps in the implementation of these schemes.



Methodology:

This study pioneers a collaborative approach, co-creating research instruments with parents for a nuanced understanding. A mixed-methods design employs a quantitative survey to gauge awareness, qualitative interviews for depth, and Photovoice for visual narratives. Ethical dialogues integrate ethical considerations. This distinctive methodology embraces innovation, fostering inclusivity and responsiveness in researching government schemes for children with special challenges.

Government Schemes for Children's with Special Challenges

- **Sarva Shiksha Abhiyan (SSA):** A flagship program for the universalization of elementary education, focusing on inclusive education.
- **Rashtriya Bal Swasthya Karyakram (RBSK):** A health program that provides free health check-ups and treatment for children below 18 years, including early identification and intervention for disabilities.
- **Unique Disability ID (UDID) card initiative:** The Unique Disability ID (UDID) card initiative provides a universal ID for persons with disabilities. The UDID card can be used to access government schemes and services.
- **DISHA Scheme:** The DISHA Scheme, implemented under the aegis of the Ministry of Social Justice and Empowerment, offers early intervention and school readiness services for children with disabilities. For children up to 10 years old with Autism or ADHD, this scheme is designed to foster the essential skills required for successful schooling.
- **NIRAMAYA Health Insurance Scheme:** Healthcare is a significant aspect of support for children with Autism and ADHD. The NIRAMAYA Health Insurance Scheme provides affordable health insurance coverage for persons with Autism, ADHD, and other disabilities. The scheme covers a broad range of medical expenses, including hospitalisation, surgery, and outpatient care.
- **GYAN PRABHA Scheme:** The GYAN PRABHA Scheme encourages people with Autism and ADHD to pursue educational and vocational courses. The scheme offers financial assistance, scholarships, and fellowships to students with disabilities.
- **Inclusive Education for the Disabled at the Secondary Stage (IEDSS):** A scheme aimed at providing inclusive education to students with disabilities at the secondary level.
- **National Handicapped Finance and Development Corporation (NHFDCC):** NHFDCC provides financial assistance for self-employment and skill development to persons with disabilities.
- **National Trust Act:** Under this act, the National Trust provides support and opportunities for persons with autism, cerebral palsy, mental retardation, and multiple disabilities.
- **Accessible India Campaign (Sugamya Bharat Abhiyan):** A nationwide campaign for universal accessibility, ensuring barrier-free access for persons with disabilities.
- **National Action Plan for Skill Development of Persons with Disabilities (NAPSDoP):** Focuses on enhancing employability and entrepreneurship of persons with disabilities.
- **Accessible E-Textbooks (Sugamya Pustakalaya):** An initiative to provide accessible e-books for students with print disabilities.
- **Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP Scheme):** Providing financial assistance for aids and appliances to persons with disabilities, including children.

- **Scholarship Schemes:** Various scholarship programs are available for students with disabilities, providing financial assistance for their education.
- **Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PMJAY):** The health insurance scheme provides financial protection to vulnerable families, including those with children facing special challenges.
- **Integrated Child Development Services (ICDS):** The program includes interventions for children with developmental delays and disabilities, focusing on nutrition and health.
- **Pradhan Mantri Matru Vandana Yojana (PMMVY):** While not specific to special challenges, it provides financial assistance to pregnant women and lactating mothers for the first living child.
- **Deendayal Disabled Rehabilitation Scheme (DDRS):** DDRS supports rehabilitation services and projects for persons with disabilities, including children.

The role of parents in the development of children with special challenges.

Parents play a crucial role in the development of children with special challenges, contributing to various aspects of their physical, emotional, social, and cognitive well-being. Here are key roles that parents play in supporting the development of children with special challenges:

1. Advocacy and Empowerment:

- Parents often serve as advocates for their children, ensuring they receive appropriate services and accommodations.
- Empowering parents with knowledge and skills to navigate educational and healthcare systems enhances their ability to advocate effectively.

2. Emotional Support:

- Emotional support is fundamental. Providing love, encouragement, and a positive emotional environment fosters the child's self-esteem and resilience.
- Addressing emotional needs helps children cope with the challenges they may face due to their conditions.

3. Educational Support:

- Parents collaborate with educators to create Individualized Education Programs (IEPs) or specialized learning plans tailored to the child's needs.
- Reinforcing learning at home and participating in educational activities enhances the child's overall development.

4. Access to Healthcare:

- Facilitating access to healthcare services, therapies, and medical interventions is a critical role.
- Consistent monitoring of the child's health, adherence to treatment plans, and communication with healthcare professionals are essential.

5. Creating Inclusive Environments:

- Parents work towards creating inclusive environments both at home and in the community.



- Encouraging social interactions with peers and promoting a sense of belonging contribute to the child's social development.
- 6. Skill Development:**
 - Parents actively engage in developing the child's skills, whether they are cognitive, motor, or social.
 - Encouraging independence and focusing on the child's strengths contribute to skill development.
- 7. Crisis Management:**
 - Addressing crises effectively, whether related to health, education, or social situations, is part of the parental role.
 - Developing resilience and problem-solving skills in both the child and the family is crucial.
- 8. Promoting Independence:**
 - Encouraging independence in daily activities promotes the child's sense of autonomy and self-efficacy.
 - Gradually introducing responsibilities appropriate to the child's abilities fosters growth.
- 9. Building a Support Network:**
 - Establishing connections with other families facing similar challenges provides emotional and practical support.
 - Networking with support groups and organizations can offer valuable resources and information.
- 10. Continuous Learning:**
 - Parents engage in continuous learning about their child's condition, treatment options, and available support services.
 - Staying informed empowers parents to make informed decisions and actively participate in their child's development.

The role of parents is dynamic and evolves as the child grows. Recognizing and supporting the unique strengths and needs of each child contributes to their overall well-being and success in overcoming challenges. Additionally, fostering a collaborative relationship with professionals and educators enhances the effectiveness of parental support.

Challenges of parents of children with special challenges.

Parents of children with special challenges face a range of difficulties that can vary depending on the nature and severity of their child's condition. Here are some common challenges:

1. Emotional Strain:

- **Stress and Anxiety:** Parents may experience heightened stress and anxiety due to the uncertainties and challenges associated with their child's condition.

- **Grief and Loss:** Coming to terms with the fact that their child may face limitations or a different developmental trajectory can lead to feelings of grief and loss.
- 2. Financial Struggles:**
 - **Medical Costs:** Specialized medical care, therapies, and assistive devices can be expensive, placing a significant financial burden on families.
 - **Reduced Work Opportunities:** Parents may need to reduce work hours or leave employment altogether to attend to their child's needs, impacting the family income.
- 3. Time and Energy Demands:**
 - **Intensive Care Requirements:** Children with special challenges often require more time and attention, leaving parents with limited personal time and energy.
 - **Balancing Responsibilities:** Juggling caregiving responsibilities with work, household tasks, and personal needs can be challenging.
- 4. Navigating the Healthcare System:**
 - **Advocacy:** Parents often need to advocate for their child within the healthcare system, dealing with complex medical information and coordinating various aspects of care.
 - **Coordination of Services:** Coordinating therapies, medical appointments, and other services can be time-consuming and challenging.
- 5. Educational Struggles:**
 - **Navigating the Education System:** Ensuring that their child receives an inclusive and appropriate education may require ongoing efforts and advocacy.
 - **Understanding Special Education Laws:** Parents may need to familiarize themselves with special education laws and advocate for their child's rights within the educational system.
- 6. Impact on Siblings:**
 - **Attention Imbalance:** Siblings may feel the impact of the extra attention and time dedicated to the child with special challenges, potentially leading to feelings of neglect or resentment.
 - **Education and Support:** Parents may need to provide additional emotional support and education for siblings to help them understand and cope with their brother or sister's condition.
- 7. Social Isolation:**
 - **Limited Social Opportunities:** Parents may find it challenging to engage in social activities due to the unique needs and demands of their child.
 - **Stigma and Misunderstanding:** Social stigma and misunderstandings from others can lead to feelings of isolation and a lack of support.
- 8. Uncertain Future:**
 - **Long-Term Planning:** Planning for the future, especially in terms of the child's independence and financial security, can be uncertain and emotionally challenging.
- 9. Health and Well-Being:**
 - **Physical and Mental Health:** The constant demands of caregiving can take a toll on parents' physical and mental well-being, requiring attention to self-care.



10. Advocacy Fatigue:

- **Continuous Advocacy:** The need for continuous advocacy for the child in various aspects of life can lead to fatigue and burnout.

Despite these challenges, many parents find strength and resilience in the journey of raising a child with special challenges. Support networks, access to resources, and a positive mindset can contribute to better coping and adaptation for parents and their families.

Recommendations and Suggestions:

Recommendations and Suggestions for parents of children with special challenges are diverse, tailored to each child's unique needs. Here are some general guidelines that may prove beneficial:

- ❖ **Seek Professional Guidance:** Consult specialists, therapists, and healthcare professionals for a comprehensive understanding of your child's needs and guidance on suitable interventions.
- ❖ **Build a Support Network:** Connect with fellow parents sharing similar challenges to gain emotional support and practical insights.
- ❖ **Stay Informed:** Keep abreast of current research, therapies, and educational approaches relevant to your child's condition, enabling informed decision-making and effective advocacy.
- ❖ **Collaborate with Educators:** Foster open communication with teachers and school staff, actively participating in the development of Individualized Education Programs (IEPs) to meet your child's educational needs.
- ❖ **Encourage Independence:** Cultivate independence by providing age-appropriate opportunities for your child, promoting confidence and essential life skills.
- ❖ **Create a Structured Environment:** Establish predictable routines and a structured home environment to offer comfort to children with special challenges.
- ❖ **Promote Social Interaction:** Support your child's social development by encouraging interactions with peers, organizing playdates, and participating in community events.
- ❖ **Celebrate Achievements:** Acknowledge and celebrate your child's accomplishments, fostering motivation and building self-esteem.
- ❖ **Take Care of Yourself:** Prioritize self-care to balance caregiving demands with personal well-being, ensuring the energy and resilience needed for effective parenting.
- ❖ **Explore Recreational Activities:** Engage your child in recreational pursuits aligned with their interests, contributing to both physical health and emotional well-being.
- ❖ **Advocate for Inclusivity:** Advocate for inclusive practices in your community, encouraging local organizations to create accessible spaces for individuals with special challenges.
- ❖ **Plan for Transitions:** Strategically plan for transitions, such as changes in educational levels or preparations for adulthood, ensuring a seamless continuum of support.
- ❖ **Utilize Assistive Technology:** Explore and leverage assistive technologies to enhance your child's independence and facilitate their learning.
- ❖ **Be Patient and Flexible:** Exercise patience, recognizing that progress may be gradual, and remain flexible in adapting to your child's evolving needs.

- ❖ **Legal Protections and Rights:** Familiarize yourself with legal protections and rights for individuals with special challenges, understanding available accommodations and services.

Remember, each child is unique, and these recommendations should be tailored to suit individual circumstances. Regular communication with professionals, ongoing learning, and participation in a supportive community contribute significantly to the overall well-being and development of children with special challenges.

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