

## Review Article

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# Understanding caregivers' needs: supporting families of autistic children

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## ABSTRACT

Parenting a child with autism spectrum disorder (ASD) poses significant emotional, financial, and social challenges to caregivers. This paper examines the experiences of caregivers, highlighting their increased stress, burnout, and mental health concerns. The importance of accessible information resources, respite care services, emotional support networks, and financial assistance programs is emphasized. Effective strategies for supporting caregivers include educating them about ASD symptoms, treatments, and therapies, teaching coping mechanisms for managing challenging behaviors, and promoting collaboration between healthcare providers and caregivers. Policy implications are discussed, including advocating for legislative modifications that prioritize caregiver needs, promoting inclusionary practices within educational systems, and increasing funding for early intervention programs and caregiver support services. The implementation of parent training programs, collaborative relationships between educators and caregivers, and professional development opportunities for educators are also recommended. This study aims to inform policymakers, healthcare professionals, and educators about the critical role of caregiver support in improving outcomes for children with ASD. By addressing caregiver needs and providing comprehensive support, we can enhance the well-being of both caregivers and children with ASD.

**Keywords:** ASD, Caregiver support, Mental health, Policy implications, Inclusionary practices

## INTRODUCTION

### *History of autism spectrum disorder*

Parenting a child can be challenging, and this becomes even more arduous when the child has a disability. It is commonly acknowledged that looking after a disabled child leads to increased stress in comparison to caring for a typically developing child. These parents experience significant stress and face challenges in parenting often accompanied by great sadness, fear, worry regarding disabled child and even disbelief they are really disabled. Parenting a child with developmental disorder may even impact family and have negative consequences on the

parents. The continual care provided to the disabled individuals can be extremely burdensome for the parent leading to mental health issues, depression, anger and stress, reduced wellbeing and poor life-satisfaction.<sup>1</sup>

### *Autism spectrum disorder: definition and prevalence*

Autism, also referred to as autism spectrum disorder (ASD), encompasses a wide range of brain development disorders. It is a neurological and developmental condition that impacts individuals' behavior, learning, social interactions, and communication. Autism falls under the category of "developmental disorder" because its symptoms typically surface within the first two years of life. According to the diagnostic and

statistical manual of mental disorders (DSM-5), individuals with ASD often experience challenges in communication and social interaction, exhibit restricted interests and repetitive behaviors, and have symptoms that affect their ability to function in various aspects of life such as school or work. Estimates from the CDC's autism and developmental disabilities monitoring (ADDM) Network suggest that approximately 1 in 36 children has been diagnosed with ASD. This condition is observed across various racial, ethnic, and socioeconomic groups. ASD is almost four times more prevalent in boys than in girls. Additionally, the frequency of autism in numerous low- and middle-income nations remains undocumented.<sup>2</sup>

## **IMPORTANCE OF CAREGIVER SUPPORT IN MANAGING ASD**

Raising an autistic child comes with specific challenges and responsibilities. The rising prevalence of ASD underscores the crucial role that parents have in supporting and caring for their autistic children.

### ***Early intervention***

National institutes of health (NIH) research has continuously demonstrated the need of early intervention in enhancing the outcomes of children with autism. As the first to identify developmental differences in their children, parents are essential in pursuing prompt intervention. Significant progress can be made in social interactions, behavior control, and communication skills by receiving an early diagnosis and implementing intervention that frequently includes therapy customized to the child's specific requirements.<sup>3</sup>

### ***Individualized support***

Since every autistic child is unique, parents are the ones who know their child's strengths, weaknesses, and triggers the best. With this knowledge, parents can work with educators and healthcare providers to develop personalised assistance programs.

The full and complete meeting of the child's unique requirements is ensured by the parents' active involvement in the creating these plans.<sup>4</sup>

### ***Daily life skills***

While neurotypical children may pick up these abilities more easily, autistic children frequently need focused help to acquire them. Parents play a crucial role in imparting fundamental life skills, such as basic communication skills and personal hygiene habits.

By being involved, parents can help their child develop independence and self-assurance, which will prepare them for more freedom as adults.<sup>4</sup>

## **THEORETICAL PERSPECTIVE FOR UNMET NEEDS OF CAREGIVERS**

Bronfenbrenner's ecological systems theory can be used to understand the unfulfilled requirements of primary caregivers of autistic children. This theoretical approach emphasizes the importance of comprehending individuals within their environments and how these environments impact them. The theory categorizes environmental systems into five: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem involves the social roles, activities, and relationships experienced directly by the individual. In the case of primary caregivers of autistic children, this system may include family, school, neighbourhood, and close relationships; thus, shaping caregiver experiences and their ability to meet their care recipient's needs. The mesosystem includes connections between microsystems and how they influence behavior; for caregivers this could involve interactions between a child and school or support services with a caregiver. Gaps within this system can contribute to unmet needs among primary caregivers. The exosystem focuses on external factors that indirectly affect an individual such as community resources or social services; in terms of caregiving for autistic children it could include interventions like financial assistance programs or support services that influence a caregiver's ability to meet their own needs as well as those of their child.<sup>5</sup>

### ***Worries and fears of caregivers raising children with ASD***

Caregivers of children with ASD expressed a range of concerns and observations about their children's behavior and development. Many believed that birth complications, such as respiratory distress or neonatal seizures, may have contributed to their child's ASD diagnosis.<sup>6</sup>

*Caregivers identified several early signs of ASD in their children, including:* Lack of eye contact at 4-6 months old, Unresponsiveness to external stimuli, Delayed speech development, Difficulty sitting and standing at an appropriate age and Unexplained crying episodes lasting 15-20 minutes at around 2-3 months old

*In addition to these early signs, caregivers reported concerns about their children's behavior, including:* Repetitive actions, Aggressive behavior leading to self-harm, Stress and anxiety caused by these behaviors, Aggression when prevented from doing something they wanted, Other concerning symptoms like continuous nodding, twitching fingers, head-banging, and tearing books

*Caregivers also noted difficulties with socialization and communication, including:* Preferring solitary play or sitting alone, displaying aggression when belongings were shared with others and struggling to form

relationships due to communication difficulties and impaired social skills

Furthermore, caregivers expressed worry about their children's future independence, well-being, and safety. They were particularly concerned about managing bodily changes during puberty, especially for female individuals with ASD, who may be more vulnerable to sexual abuse. These concerns caused significant stress and feelings of helplessness among caregivers.<sup>6</sup>

## CHALLENGES FACED BY CAREGIVERS

Parents often fail to evaluate their own sources of strength and emotions. They may be so busy meeting the needs of their child that they don't allow self-time to relax, cry or simply think. However, the journey to care for these children could be challenging and can impact the general well-being of caregivers.

### ***Increased caring responsibilities***

Bringing up a child with ASD can be challenging and call for a special set of abilities and techniques.

***Creating a secure and caring atmosphere:*** Kids with ASD may struggle with sensory processing, making them more susceptible to sounds, textures, odors, and other stimuli in their surroundings. Creating a setting that is predictable, safe, and reduces sensory overload can make kids feel safer and more at ease.

***Making sure children with ASD have access to the right therapies and interventions:*** Applied behavior analysis (ABA), speech therapy, occupational therapy, and other therapies and interventions may be beneficial. In order to determine the best therapies and make sure their child gets the assistance they need, parents and other caregivers must collaborate closely with healthcare providers.<sup>7</sup>

### ***Emotional stressors***

#### ***Coping challenging behaviour***

ASD children may display difficult behaviors including violence, self-harm, or repetitive motions. Together with healthcare professionals, parents and other caregivers must come up with plans for controlling undesirable behaviors and encouraging good behavior. Anxiety, depression, or digestive disorders are examples of co-occurring physical or mental health conditions that might affect children with ASD. In order to address these problems and make sure their child receives the right care, parents and other caregivers must collaborate with healthcare professionals.<sup>6</sup>

***Coping with diagnosis:*** It's important to keep in mind that even though a child's diagnosis of autism can be daunting, they are not alone. Many parents experience a range of

feelings following their first shock and confusion at their child's autism diagnosis, from loss and grief to denial and guilt. Getting help from friends, family, therapists, and support groups can offer a secure setting for dealing with these emotions and preparing for the trip ahead.<sup>6</sup>

***Managing emotional overload:*** Managing emotional overload is a daily challenge for every parent of a kid with autism. Emotional health can be negatively impacted by the parent's ongoing advocacy for their own child's risk, the strain of figuring out different therapies and interventions, and the concern for the child's future. Prioritizing self-care, getting expert assistance when necessary, and finding healthy ways to decompress-like engaging in hobbies, meditation, or exercise-are all essential.<sup>6</sup>

### ***Managing communication difficulties***

Parents can play a key role in a child's development by assisting with social skills. Social skills like taking turns, sharing, and maintaining eye contact can help parents and other caregivers support their child's development. Children with ASD may struggle with social communication and interaction.

### ***Dealing with social isolation***

Globally, disability stigma contributes to the stigmatization of primary caregivers of autistic children. Due to this, some families caring for disabled children may lose their sense of belonging, isolate themselves from society, and may even be forced to blame themselves for the condition of their children. Parents report that their child's autistic behaviors, combined with social stigma and isolation, make their lives more challenging, according to a new study of the Simons simplex collection (SSC). The researchers found a significant amount of isolation and even outright rejection of children and their families. More than 65 percent of the children were sometimes or often avoided or left out of activities by other kids. About 13 percent were physically bullied at least sometimes. This social isolation extended to their families. Forty percent of the parents said they isolated themselves from friends and family because of their child's autistic behaviors. And 32 percent said other people excluded them from social events and activities.<sup>8</sup>

### ***Financial burdens***

Expenses related to raising a kid with autism extend beyond the price of therapies. Similar to other types of developmental disabilities, parents of autistic children frequently have to spend more time and money. The family incurs significant expenses when their child with autism participates in extracurricular activities. Hence, compared to a child who is usually developing, caring for an autistic child involves higher costs for daycare, special education, caregiving, and family expenses. It includes high hidden expenses for different therapies and

specialized classes; insurance restrictions; and the exorbitant cost of rehabilitation classes. The long-term financial strain of raising a kid on the spectrum may weigh heavily on some parents. This could be the case in families who are not covered by insurance etc.<sup>9</sup>

**Accessing financial resources and benefits:** To support a child with autism, accessing financial resources and benefits can be challenging. Parents may struggle to navigate the complex systems in place to obtain funding for therapy, specialized education, and other necessary services.

#### *Managing therapy and treatment costs*

With the high costs of therapy and treatment for children with autism, managing expenses can be overwhelming. From speech therapy to behavioral interventions, the financial burden can quickly add up, putting a strain on families. A comprehensive approach to managing therapy and treatment costs is vital. Families may explore options such as insurance coverage, government assistance programs, and nonprofit organizations that offer financial assistance for various ASD related services. Planning ahead, budgeting, and seeking out cost-effective alternatives can also help alleviate the financial strain.<sup>9</sup>

#### *Balancing financial priorities*

Families who have a kid diagnosed with ASD must learn to juggle their financial priorities. In addition to wanting to give their child the finest care and assistance possible, parents often have other financial responsibilities, such as paying for their daily needs, a mortgage, and future savings. The secret is to design a financial strategy that addresses other risk factors to the family's general financial health in addition to the special demands of the autistic child. Developing a sustainable financial plan may benefit from professional financial counselling and assistance from those who are aware of the difficulties associated with parenting an autistic child.<sup>9</sup>

### **IMPACT ON CAREGIVER HEALTH**

#### *Addressing sleep disturbances and gastrointestinal issues*

Parents may have excessive worries about their child's physical health when they are experiencing signs of autism. Gastrointestinal problems and sleep difficulties are frequent problems that many families deal with early on. In order to properly handle these concerns, it is crucial to confer with healthcare professionals. Three studies that looked at parents, siblings, or moms in particular showed signs of physical strain on family caregivers. According to qualitative data, parents experienced long-lasting medical ailments, and it was hypothesized that this was due to ongoing stress and anxiety over caring for their autistic kid. Living together

with an adult child with ASD is associated with stress and exhaustion, according to a mixed-method study.<sup>10</sup>

#### ***High levels of stress and burnout***

Taking care of a kid with autism may be extremely taxing, which frequently leads to caregiver burnout and increased stress. Caring frequently encounters challenging behaviors, communication difficulties, and isolation due to their child's condition, contributing to heightened emotional strain. Prolonged stress may result in burnout syndrome characterized by emotional exhaustion, depersonalization, and reduced personal accomplishment. While caring for a loved one can be very rewarding, it also involves many stressors. And since caregiving is often a long-term challenge, the emotional impact can snowball over time. Caregivers may face years or even decades of caregiving responsibilities. It can be particularly disheartening if there's no hope that the child will get better, or if, despite the best efforts, their condition is gradually deteriorating. If the stress of caregiving is left unchecked, it can take a toll on the health, relationships, and state of mind—eventually leading to burnout, a state of emotional, mental, and physical exhaustion.<sup>1</sup>

#### ***Common signs and symptoms of caregiver stress include***

Anxiety, depression, irritability, feeling tired and run down, difficulty sleeping, overreacting to minor nuisances, new or worsening health problems, trouble concentrating, feeling increasingly resentful, drinking, smoking, or eating more, neglecting responsibilities and cutting back on leisure activities.

***Common signs and symptoms of caregiver burnout:*** Less energy, feeling ill flu-like symptoms, constantly exhausted, even after sleeping or taking a break, neglect once own needs, trouble relaxing, even when help is available, impatient and irritable with the child and helpless and hopeless.

#### ***Increased risk for depression and anxiety disorders***

More than half of caregivers show signs of clinical depression and caregivers take more prescription medications, including those for anxiety and depression than others in their age group. The toll that raising a kid with autism spectrum condition may have on parents' mental health is one of the most difficult aspects of the job. The constant worry, stress, and often overwhelming responsibilities can lead to anxiety and depression. It is crucial for parents with ASD to prioritize self-care and seek support from therapists or support groups.<sup>11</sup>

#### ***Impact on marital relationships***

An autistic child's diagnosis can drastically alter a married couple's lives. Marriages can suffer greatly from the strain and difficulties of raising a child with special

needs. These couples may experience difficulties due to shifting family dynamics, financial strains, emotional strain, and the added responsibilities of caregiving.<sup>11</sup>

## STRATEGIES TO SUPPORT CAREGIVERS

### **Accessible information resources**

#### *Education about ASD symptoms, treatments, therapies*

Education is an empowering tool for parents of autistic children. Being well-informed about ASD equips parents to make informed decisions, advocate for their child's needs, and collaborate effectively with professionals. Workshops, webinars, and information-sharing sessions offered by dedicated social organisations serve to enhance parental knowledge and confidence in managing their child's autism.<sup>12</sup>

#### *Information available community resources.*

*Autism society:* This organization provides support groups, caregiver education, and resources for families affected by autism.

*National alliance on mental illness (NAMI):* NAMI offers support groups and educational programs for caregivers of individuals with mental health conditions, including autism.

*Local support groups:* Check with local community centers, churches, or schools for support groups specifically for caregivers of autistic children.

*Respite care services:* These services provide temporary relief to caregivers by offering trained professionals who can care for the child with autism while the caregiver takes a break.

*Parent training programs:* Many communities offer training programs specifically designed to help parents and caregivers learn effective strategies and techniques to manage behaviors associated with autism.

*Autism treatment centres:* These centres often have resources such as counselling services, parent training programs, and social skills groups available to support caregivers.

*Online support communities:* There are various online forums and communities where caregivers of children with autism can connect with others facing similar challenges and share experiences and advice.<sup>12</sup>

Teaching coping strategies for dealing with challenging behaviors.

Some of the hardest parts of raising a child with autism are the behavioral difficulties repetitive behaviors that can arise. These repetitive patterns and difficulties can

manifest in various ways and present unique challenges for parents and caregivers.<sup>11</sup>

### *Handling meltdowns and tantrums*

One of the most challenging aspects is handling meltdowns and tantrums. These can be triggered by a variety of environmental factors, and can be overwhelming for both the child and the caregiver.<sup>13</sup>

### *Establishing routines and structure*

For kids with autism, structure is crucial. For kids with ASDs, routines and structure can assist provide them a sense of security and predictability, which is consoling. Reducing anxiety and enhancing behavior patterns can be achieved by establishing a regular daily routine and setting clear expectations.<sup>11</sup>

### *Encouraging communication and social skills*

To encourage both communication skills, and social skills, it's important to create opportunities for interaction and support language development. This may involve using visual aids, social stories, or other tools to help the child communicate their needs and understand social cues. Understanding the child's unique communication style and preferences is key to fostering their brain development, positive social interactions and building strong relationships.<sup>13</sup>

## RESPITE CARE SERVICES

Utilize respite care services to ensure caregivers have regular breaks to recharge. Respite care services are designed to provide temporary relief to caregivers of individuals with autism. These services offer trained professionals who can care for the individual with autism, allowing the caregiver to take a break and attend to their own needs. Respite care can be provided in-home or at a specialized facility, and it offers caregivers an opportunity to rest and recharge while ensuring their loved one's needs are still met.<sup>15</sup>

### *Temporary relief from caregiving responsibilities.*

Respite care services provide temporary relief from caregiving responsibilities for individuals caring for someone with autism. This allows caregivers to take a break, attend to personal needs, and recharge while ensuring that their loved one's care needs are still met by trained professionals. Respite care can be an essential support for caregivers, helping them avoid burnout and maintain their own well-being.<sup>16</sup>

### *Opportunities for self-care and rejuvenation*

Caregivers often neglect their own self-care needs while focusing on the needs of their loved ones. It is important for caregivers to create opportunities for self-care and

rejuvenation. This can include activities such as exercising, practicing mindfulness or meditation, engaging in hobbies or interests, spending time with friends and family, or simply taking some time alone to relax and recharge. By prioritizing self-care, caregivers can reduce stress levels and maintain their physical and mental well-being, ultimately allowing them to provide better care for their loved ones with autism.<sup>16</sup>

## EMOTIONAL SUPPORT NETWORKS

### ***Establish support groups or online communities where caregivers can share experiences.***

Establishing support groups or online communities for caregivers can be a valuable resource for sharing experiences, gaining support, and finding practical tips and advice. These groups provide a safe space for caregivers to connect with others who are facing similar challenges and can understand their unique experiences. By sharing their knowledge and experiences, caregivers can potentially improve the quality of care they provide for their loved ones.<sup>17</sup>

### ***Access to counselling services or therapy sessions to address caregiver mental concerns***

Having access to therapy sessions or counselling services might be crucial in helping caregivers with their mental health issues. Due to the emotional strain of caring for a loved one with autism, caregivers may develop stress, anxiety, despair, and burnout. For this reason, it is essential to give caregivers access to competent mental health support in order to ensure their wellbeing. Caregivers may find a secure and private setting in counselling or therapy sessions to process their experiences, express their feelings, and create coping mechanisms. Along with teaching caregivers how to prioritize self-care, create boundaries, and successfully manage stress, these sessions can also assist caregivers learn how to fulfill their caregiving responsibilities.<sup>17</sup>

## FINANCIAL ASSISTANCE PROGRAMS

To support a child with autism, accessing financial resources and benefits can be challenging. Parents may struggle to navigate the complex systems in place to obtain funding for therapy, specialized education, and other necessary services.

### ***Grants or subsidies for therapeutic interventions or specialized equipment expenses.***

Providing grants or subsidies for therapeutic interventions or specialized equipment expenses can greatly benefit caregivers of individuals with autism. As part of the caregiving responsibilities, caregivers often incur significant financial costs related to accessing specialized therapies and purchasing equipment that can support the individual with autism. For people with autism to flourish

and acquire necessary abilities, therapeutic interventions like speech therapy, occupational therapy, behavioral therapy, and other types of specialized interventions are frequently crucial. These services, however, can be expensive, and insurance may not always cover the whole cost of them. By offering grants or subsidies to offset these expenses, caregivers can access the necessary therapies without facing financial strain. Similarly, individuals with autism may require specialized equipment such as communication devices, sensory tools, adaptive furniture, or safety devices to support their unique needs. These items can also come with a hefty price tag.<sup>18</sup>

### ***Educating people about the tax advantages and benefits that are available to families with children***

Encouraging people to know about the tax credits and benefits that are available to families raising children with autism is essential to helping caregivers financially. Numerous governments provide financial aid in the form of tax credits, deductions, or other advantages to families with children who have disabilities, including autism.

By educating caregivers about these available resources, they can take advantage of potential tax relief and financial assistance. This can include the child disability benefit (CDB) in Canada, the Disabled dependent care credit in the United States, or similar programs in other countries. Additionally, some regions offer additional grants or subsidies that are specifically designed to support families caring for children with special needs. Furthermore, providing information on how to navigate the process of applying for these benefits can be invaluable. Many parents may not be aware of their eligibility or how to access these supports without proper guidance.

In India one such program is the disabled dependent deduction under Section 80DD of the Income Tax Act, which allows for a deduction from taxable income for expenses incurred on medical treatment, training, rehabilitation, or nursing of a disabled dependent. Additionally, there are various state-specific welfare schemes and benefits that provide financial aid to families caring for children with disabilities.<sup>19</sup>

### ***Promoting collaboration between healthcare providers and caregivers***

Interprofessional collaboration in healthcare has gained significant attention in recent years, and for good reason. It's a practice that involves healthcare professionals from various disciplines working together to deliver the best possible patient care. This collaborative approach goes beyond traditional silos, promoting teamwork and communication among doctors, nurses, pharmacists, therapists, and other healthcare providers. Each expert brings their knowledge and insights to share with other

sectors, which can have a profound impact on patient outcomes, safety, and overall healthcare delivery.<sup>20</sup>

### **Ensuring open communication channels between healthcare providers and caregivers in order to address concerns effectively**

Clear and open communication between caregivers and patients is essential for establishing a strong caregiver-patient relationship, benefiting the patient's well-being and recovery. When communication is effective, patients feel comfortable discussing health concerns and sharing personal information, enabling caregivers to understand their needs and provide tailored care. Building trust is another advantage of good communication. Patients who trust their caregivers are more likely to adhere to care plans, follow prescribed medications, and report issues honestly.<sup>21</sup>

### **Empowering caregivers through training programs that aim at teaching them coping strategies**

Many kids with autism and other developmental impairments don't have access to high-quality treatment and interventions around the world. The world health organization (WHO) created the caregiver skills training (CST) for families of children with developmental delays or disabilities in order to assist these families, with funding from autism speaks. The evidence-based CST program is provided free of charge to families, equipping parents and other caregivers with the daily skills necessary to support their children in realizing their full potential. Everyday play and household routines are emphasized as ways for caregivers to support their child's development of healthy behavior, communication, and everyday living skills. In addition, caregivers gain critical problem-solving and self-care abilities to enhance their confidence, lower their stress levels, and enhance their general wellbeing while learning how to better support their children.<sup>22</sup>

### **Spirituality**

Understanding oneself and oneself in relation to others and the absolute through spirituality may increase resilience-promoting potential and help families of autistic children cope with their child's condition. Spiritual education and self-practice, presented through lectures, group discussions, and experiential activities, can be a part of a spiritual program.<sup>22</sup>

## **POLICY IMPLICATIONS**

### **Advocate for legislative modifications that give caregiver needs a priority**

Promoting policy changes that provide caregiver requirements for children with autism first priority is essential to enhancing their well-being and guaranteeing them equitable chances. Numerous research studies have

emphasized the substantial challenges faced by parents of autistic children, such as elevated stress levels, economic hardship, and social distancing. In spite of these obstacles, comprehensive programs that address the particular requirements of these families are lacking. Therefore, in order to successfully address these concerns, pushing for changes to policy becomes vital.

**Tax deductions for expenses:** One potential policy change could be the introduction or expansion of tax credits and benefits specifically tailored towards families caring for children with autism. This could include tax deductions for expenses related to therapy sessions, specialized equipment or adaptive technology devices, respite care services, and other necessary support services.

**Increased funding and accessibility to early intervention:** Additionally, advocating for increased funding and accessibility to early intervention programs can greatly benefit both caregivers and children with autism. Early intervention has been proven to be highly effective in improving outcomes for individuals on the spectrum. By ensuring that these programs are easily accessible and affordable for all families regardless of their socio-economic status, policymakers can alleviate some financial burden from caregivers while also providing essential support services.

**Caregiver-friendly workplace:** Another important aspect is promoting caregiver-friendly workplace policies such as flexible working hours or remote work options. Providing accommodations like these can enable caregivers to balance their responsibilities at home while also maintaining employment opportunities.

**New policies:** Furthermore, it is crucial that policymakers collaborate closely with relevant stakeholders such as parent advocacy groups, healthcare professionals specializing in autism care, educators who work directly with autistic individuals - both mainstream schools where inclusion is encouraged and special education schools, when formulating policies related to caregiver support.<sup>22</sup>

In conclusion, it is critical to promote legislative changes that give caregiver needs unique to children with ASD top priority in order to provide appropriate support.

## **PROMOTING INCLUSIONARY PRACTICES WITHIN EDUCATIONAL SYSTEMS**

Encouraging inclusionary practices in educational systems is essential if we want to make sure that parents of autistic children have the help and resources they need to satisfy their child's special requirements.

### **Inclusive education**

It refers to the practice of educating all students, regardless of their abilities or disabilities, in a general education setting. It emphasizes providing appropriate

accommodations and support services to enable students with autism to fully participate in mainstream classrooms alongside their neurotypical peers. However, it is equally important for these inclusive practices to extend beyond just the students and include support for their caregivers as well.<sup>22</sup>

### ***Implementation of parent training programs within schools***

One effective policy change could be the implementation of parent training programs within schools that focus on providing parents and caregivers with strategies and resources tailored specifically towards supporting autistic individuals in an inclusive educational environment. These training programs can help empower parents by equipping them with knowledge about evidence-based interventions, behavior management techniques, and communication strategies. They can also provide guidance on advocating for their child's rights and accessing appropriate support services.<sup>23</sup>

### ***Collaborative relationship between educators and caregivers***

Another important aspect is establishing a collaborative relationship between educators and caregivers through regular communication channels. This can include parent-teacher conferences, individualized education plan (IEP) meetings where goals are set collaboratively between teachers and parents/caregivers based on each child's specific needs, or even digital platforms where real-time updates about a student's progress can be shared with parents/caregivers.<sup>23</sup>

### ***Professional development opportunities for educators***

Additionally, promoting professional development opportunities for educators focused on understanding ASDs can enhance their capacity to effectively support both students with ASD and their caregivers. These professional development initiatives should cover topics such as creating inclusive classroom environments, implementing evidence-based teaching strategies specific to ASD learners' needs, fostering social skills development in autistic individuals within mainstream classrooms.<sup>24</sup>

### ***Increased funding allocation***

Furthermore, advocating for increased funding allocation towards hiring additional staff members such as special education teachers or paraeducators who have expertise in supporting autistic individuals within mainstream educational settings would further facilitate inclusionary practices while alleviating some burden from classroom teachers. In conclusion, promoting inclusionary practices within educational systems requires policymakers' attention towards implementing policies that address

caregiver needs while acknowledging diverse strengths among autistic learners.<sup>24</sup>

## **CONCLUSION**

Heroes are the parents of autistic children. They act as a network of support and facilitators for talented people with exceptional skills. Every day is unique and presents the family with chances as well as challenges. Being patient is a characteristic that is absolutely necessary while raising a child with autism. The path is unlike any other; it is full of obstacles that put to the test not just resilience but also the capacity for adaptation and seeing the world from their perspective. Every day brings new challenges to be met with love and patience, such as overcoming communication difficulties and navigating sensory sensitivity.

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